
Preventing the Human Time Bomb

Geographies of Diabetes Education in New Zealand

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For my Mum, Dad and brother

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ABSTRACT

This thesis examines the quality and effectiveness of diabetes education in New Zealand. It is said that a global diabetes epidemic is underway. If diabetes rates increase as predicted it will become one of the world's main public health problems. Diabetes also presents a huge burden, socially and economically to societies. Education is perhaps one of the most modifiable social determinants of health. Education is vital for diabetes, due to the importance of self care, the severity of complications that can result, to create awareness and help prevent an initial diagnosis.

There are many ways in which people can receive diabetes education. One educational provider of importance, in New Zealand is Diabetes New Zealand (DNZ). DNZ is a voluntary organisation and has 41 affiliated societies across New Zealand. In order to improve diabetes educational services and help reduce the burden of diabetes in society it is necessary to gain an understanding of diabetes educational provision.

Geography, with its fusion of place and people can offer a valuable contribution to the study of diabetes education. There has been a lack of attention given to public health issues by geographers. A health geography approach that incorporates the concept of place is important as it can provide insight into the way in which people experience different educational spaces. By focusing on aspects of the local environment and investigating elements of place, for example, rural and urban environments or health system organisation, another dimension to understandings of health and people's experiences within health care environments can be obtained.

This thesis argues that to improve patient education and diabetes outcomes, people's perceptions and experiences within diabetes educational spaces must be investigated and understood. In addition, the extent to which diabetes educational spaces are utilised must also be explored if educational services are to be improved.

The diabetes societies in New Zealand have a vital role in the provision of diabetes education for members. However, there are variations among members' perceptions and experiences within this educational space. To improve educational services, the extent to which they are utilised must also be explored. Again, it is necessary to gain an insight into the perceptions of the consumers, in relation to utilisation, to obtain a holistic understanding of diabetes educational services in New Zealand. A geographical approach to exploring the role of the voluntary sector in diabetes educational provision also provides insight into the geographies of voluntary organisations involved in diabetes education.

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CHAPTER 1

The Diabetes Epidemic, a Silent Killer:

Introduction and Thesis Aims

It happened when we were in seventh form. My friend was told in a matter of days that she could have slipped in to a coma, and possibly died. Several weeks later she asked me to watch her 'shoot up', saying she wouldn't leave the room to do it. I was anxious, but witnessed a life saving process. However, the insulin didn't do its job properly and while we were sitting at the common room table she became increasingly grey, pale and shaky. I didn't know what to do, let alone what was happening. Seeing my confusion she told me it was a 'hypo', which meant low blood sugars, and asked me to get some orange juice.

1.1 Foreword

This experience during high school gave me an insight into what it means to have diabetes and its severity. At the time I knew nothing about diabetes and was interested to learn. I was grateful that my friend was able to answer my questions and talk openly with me. Through our discussions I became increasingly aware of the importance of having a comprehensive understanding and awareness of diabetes. Given the implications of diabetes the need for education is vital for self-care, diabetes management and ultimately, for survival. However, it was also important that I was aware and had an understanding of diabetes so I would know what to do should a 'hypo' occur again.

Previous research indicates that the local delivery of diabetes education in New Zealand is uneven (Simmons et al 1994a). Therefore it is necessary to investigate the geographies of diabetes education. However, to really understand diabetes education in New Zealand an exploration of diabetes education from the inside, from the point of view of the people with diabetes who actually receive the education is imperative.

Therefore, this thesis argues that to improve patient education and diabetes outcomes, people's perceptions and experiences within diabetes educational spaces must be investigated and understood. In addition, the extent to which diabetes educational spaces are utilised must also be explored if educational services are to be improved.

1.2 Why Study Diabetes Education?

Education is perhaps one of the most modifiable social determinants of health (Beaglehole and Bonita 1997). Education is important for diabetes, especially given the severity of complications that can result and in relation to managing blood-glucose levels effectively. Therefore, education is important for diabetes self-care and self-management. Educational and preventative strategies at the community level are also important for helping to increase awareness and reduce the burden of diabetes in society. There are many ways in which people with diabetes can receive diabetes education. One educational provider of particular importance in New Zealand is Diabetes New Zealand (DNZ) and the 41 affiliated Diabetes Societies. This voluntary organisation has an important role within the network of diabetes care and educational providers. An exploration of members' perceptions and experiences surrounding the role of the diabetes society can provide valuable insights into the quality and effectiveness of this education. It is important to study diabetes education because rates of diabetes are now reaching epidemic proportions (King et al 1998; Hux 2002; WHO 2002a; Diamond 2003; Efrat 2003; Stovring et al 2003; Wild et al 2004; Young 2004). Given the modifiable risk factors associated with type 2 diabetes, it is necessary to investigate ways in which the burden of diabetes can potentially be reduced.

Diabetes, which has been referred to as a 'silent killer', affects between 171 and 177 million people worldwide (Dunstan et al 2002; Diamond 2003). The global incidence of diabetes is increasing and it is argued that a diabetes epidemic is underway (King et al 1998; Hux 2002; World Health Organisation (WHO) 2002a; Diamond 2003; Efrat 2003; Stovring et al 2003; Wild et al 2004; Young 2004). The number of people with diabetes is expected to increase markedly in the next thirty years, exacerbating the social and economic burden for society (King et al 1998; WHO 2002a; WHO 2002b; WHO 2002c; Wild et al 2004). The global prevalence of diabetes is expected to

nearly double, from 2.8% of the total population in the year 2000 to 5–5.4% of the total population by the year 2030 (King et al 1998; Wild et al 2004).

Diabetes is a complex, chronic disorder and is characterised by an elevation in blood-glucose levels (hyperglycaemia) within the body. If left untreated, hyperglycaemia can result in a coma or even death. Diabetes is associated with a lack of insulin action and/or insulin secretion (Songer and Zimmet 1995). There are two types of diabetes, type 1 and type 2. Type 1 and type 2 differ in their onset, as they have an acute and insidious inception, respectively. Unlike a heart attack or a stroke, diabetes is not an immediate threat to life. However, many people with diabetes are unaware of the devastating and severe complications of both type 1 and type 2 diabetes, which if left untreated, can be fatal (Barnett et al 2001).

Diabetes is a serious problem in New Zealand. In 2001 the Ministry of Health (MoH) estimated that around 115,000 people had diabetes. The Ministry of Health (2002a; 2002b) predicted that the incidence of diabetes is likely to increase by two-thirds from 1996 to 2011. A further 60,000 people are thought to have diabetes but remain undiagnosed (MoH 2002a; 2002b).

There are important variations in diabetes rates between different sub-groups of the New Zealand population. Maori and Pacific Islanders are three times more likely to develop diabetes than Europeans. The prevalence of diabetes, in the population over 15 years of age, was 8.1% for Pacific Islanders, and 8.3% for Maori, compared with only 3.1% for Europeans (Health Funding Authority (HFA) 2000; MoH 2002b). Maori and Pacific Island peoples are more likely to be obese than any other group in New Zealand and are at a higher risk of being diagnosed with diabetes (de Lore et al 1993). Certain populations, such as Pacific Islanders, are genetically predisposed to gain weight and store fat, thus increasing the risk of developing diabetes (Moore and Lunt 2000).

However, along with population-based or compositional factors, geographical or contextual factors are also important. According to Davis and Dew (1999) and Evans et al (2000) there were more people who were obese and had diabetes in more deprived areas. The Ministry of Health (1999) also state that people living in more deprived areas tended to have higher rates of diabetes. Furthermore, it is known that

Maori and Pacific Island peoples are relatively socio-economically disadvantaged in comparison to other groups within New Zealand (Davis and Dew 1999). Therefore, the increased prevalence of diabetes among these groups of the New Zealand population cannot be seen in isolation from environmental factors, such as deprivation, urbanisation and the nature and availability of health care resources. It is currently thought, however, that both genetic and environmental factors are involved in type 1 and type 2 diabetes. The exact role of genetic and environmental factors and how they interact remains controversial (Belchetz and Hammond; 2003 Ravussin et al 1994).

The disparities in diabetes rates that exist between different groups of the New Zealand population may be linked to the utilisation of diabetes education and educational services. Therefore it is essential to investigate the extent to which diabetes educational services are utilised. The inequalities in health status within New Zealand have important implications for public health and public health planning. Public health and associated ideologies have shaped responses to the diabetes epidemic and influenced the provision of diabetes care and education in particular places. Due to the predicted increase in diabetes rates in the next decade and the severity of complications diabetes is an important public health issue. A geographical approach to exploring a public health issue like diabetes and diabetes education in New Zealand is appropriate because the nature of variations in diabetes rates and the uneven delivery of diabetes education are inherently geographical

1.3 Situating the Diabetes Epidemic within the Realm of Geography

The concept of place¹ is important for health geography and is relevant when looking at public health issues like diabetes. Geography, with its fusion of people and place offers a powerful approach and can provide a valuable insight to the investigation of health-related issues. Gesler (1991) asserts that geographers interested in health must pay attention to the symbolic content of landscapes and places as this gives important insights to the understanding of health. To enhance our understanding of the symbolic nature of, for example the primary health care, landscape it is necessary to

¹ It is acknowledged that 'place' is also a highly contested term. There are various definitions and contested meanings between different people and places (Curtis et al 2004).

emphasise the culture that surrounds the geography of health care consumption (Kearns and Barnett 1997).

The study of place effects has been an important and recent development within the field of health geography. A geographical approach that incorporates an investigation of place attempts to elucidate how features of the local environment, material infrastructures and shared social functioning interact and influence people's health status and health-related behaviour (Macintyre et al 2002; Moon and Barnett 2003; Curtis et al 2004). Features of the local environment may relate to the organisation of the local health system, the availability of health care resources or whether a place is situated within a rural or urban context.

An incorporation of the concept of place in health geography, allows for an examination of the interactions and relationships between different constructs of place, along with exploring the links between social theories (Gesler 1992; Kearns and Joseph 1993; Dyck 1999; Johnston et al 2002). Gesler (1991, p167) argues that "geographic studies rarely pay much attention to the meaning of places in health care delivery... *Where* a hospital lies within a spatial distribution is given more importance than *what goes on* within that particular hospital". The recognition of the importance of place for health and health-related behaviours has also led to a more intensive qualitative research approach, which utilises in-depth qualitative methodologies. Qualitative techniques have the ability to emphasise how different people experience places and how aspects of places can shape people's health behaviours, beliefs and attitudes (Kearns 1993; Kearns and Joseph 1993; Kearns 1994; Kearns and Moon 2002; Johnston et al 2002).

Previously, medical geography has dominated geographical inquiries within the field of health. Medical geography was situated within the biomedical model of health (Joseph and Phillips 1984; Kearns and Moon 2002; Gatrell 2002). Two main perspectives that have influenced medical geography research on health and health care relate to access and utilisation, and disease ecology. Epidemiology has also influenced medical geography. Epidemiology studies the distribution patterns of diseases and disorders and attempts to provide an insight into the determinants of disease frequencies. Medical geographers have tended to focus on spatial and locational variations of disease frequency to provide understandings of causality

(Joseph and Phillips 1984; Jones and Moon 1987; Gatrell 2002). Such studies sought to uncover the aetiology of a disease by establishing a testable hypothesis in an objective manner (Joseph and Phillips 1984; Scarpaci 1988; Barnett et al 2000; Gatrell 2002). However, medical geography has been criticised for its lack of attention to people and aspects of the social environment (Kearns and Moon 2002).

The emergence of place has become a framework for helping to understand health, and specific public health issues like diabetes (Kearns 1994; Kearns and Moon 2002; Dyck 1999). Given that this study is aiming to investigate diabetes education from the inside, by exploring the perceptions and experiences of people who receive diabetes education, an incorporation of the concept of place is valuable. Places matter because they are the context in which health related behaviour occurs. The idea of place can be thought of as a socially constructed and a complex phenomenon (Duncan et al 1993). Places are sites which hold human intentions and values. Within places there is an intersection of social relations, collective memories and the construction of meanings along with encapsulating and communicating identities (Gesler 1991; Gesler 1992; Kearns 1994; Kearns and Barnett 1997; Kearns and Moon 2002). It is through place that identities are constructed, contested and re-negotiated (Johnston et al 2002).

Exploring ideas of place in relation to diabetes education offers insights into people's perceptions, such as satisfaction and utilisation of educational services, which may enable the implementation of more effective educational services or strategies. Focusing on aspects of the local environment and investigating aspects of place, for example, rural and urban environments or health system organisation, can add another dimension to understandings of health and people's experiences within health care environments. Thus health cannot be isolated from people or the social environment. Such an exploration allows diabetes education to be investigated in a more holistic way as elements of the social environment are incorporated (Chan et al 1994; King et al 1998; Karter 2003; Wild et al 2004).

Brown's (1988) analysis of the organisational influences on diabetes-related hospitalisation illustrates the importance of exploring place effects in relation to health. Brown (1988) investigated a particular aspect of place, the organisational structure of the health system and its influence on diabetes-related hospital admissions

in Christchurch, New Zealand (Brown 1988). Marked geographical differences were found between the regional hospital board populations in their rates of diabetes hospitalisation. Brown (1988) revealed that the variance in hospitalisation was significantly related to the supply of medical resources, especially hospital bed supply, even when socio-demographic factors were controlled for. Furthermore, in relation to a different place effect, it was found that large urban hospital boards, with a relatively low bed supply, had lower rates of diabetes-related hospitalisation. Areas with visibly higher rates of hospitalisation were commonly smaller rural based hospital boards. The observed patterns of diabetes hospitalisation reflects the provision of health care resources and hospital admission practices. Brown's research suggests that aspects of place and the local environment can influence diabetes outcomes. Her research also provides an insight into the social-environmental factors that account for some of the variations associated with diabetes-related hospitalisation.

Despite the changing nature of health geography, it has become apparent the field of public health has been largely neglected by health geographers. With the exception of Brown's (1988) analysis, geographers have not addressed diabetes in relation to public health. This is surprising given the supposed holistic nature of health geography and public health. Brown (1995; 2000) argues that scientific epistemologies often exclude alternative ways of knowing and understandings of people and places with respect to AIDS. In this respect, he calls for a more social geographic approach. However, AIDS as a public health issue and how it has been responded to in different places also needs to be addressed. Although Macintyre (1993) mentions the implications for public health that may come from focusing on people or places when investigating health issues, the need to develop an understanding of specific public health issues, like diabetes, is not illustrated. Sociologists, for example Lupton (1995) and Petersen (Petersen and Lupton 1996), have explored and critically examined the changing nature of the field of public health. However, responses to specific issues, like diabetes and diabetes education remains relatively unexplored, especially by geographers.

The inclusion of collective social functioning is important in relation to this research in order to gain an inside understanding of people's perceptions and experiences of diabetes education. Macintyre et al (2002) suggest that an exploration of the

collective dimension of health which emphasises the importance of shared norms, traditions and values must also be incorporated when investigating place effects on health. The incorporation of ideas relating to collective social function, meaning and experiences can provide a greater insight and understanding into how the local social and physical environments influence human health and health behaviours. Therefore, it is not only the characteristics of places that are important, but the interaction that occurs within places for the construction of health beliefs, behaviours and attitudes.

It is argued that the distinction between people (compositional characteristics) and place-based (contextual) characteristics can be problematic. There are variations over whether certain characteristics, of either individuals or local areas, are confounding or intervening variables. This difference would result in different conceptualisations and operation of place effects. Place effects on health may vary at different spatial scales, over time and between different population groups. However, it could be argued that the inclusion of a 'collective dimension' is also a place effect. Barnett (2000) argues that it is vital to target places and people as well as giving reference to the local geographic context and social environment. This would also serve to situate geographic research within a greater body of theory, which is important as theories can act as frameworks and ways of shaping observations and understandings of the world (Litva and Eyles 1995).

In light of this lack of attention given to public health issues by geographers and the importance of education for people with diabetes, this research takes a geographical approach and incorporates the concept of place to explore people's perceptions and experiences of diabetes education within the diabetes societies of New Zealand, as they are a key educational provider. Williamson (2004) argues that although geographies of public health are beginning to emerge, the consumption of knowledge and experiences within educational spaces has been somewhat neglected and remains relatively unexplored. Therefore, this thesis argues that it is necessary to understand what consumers think in order to improve educational services. Investigating the geographies of diabetes education within the diabetes societies will also illustrate the role of the voluntary sector for diabetes care and education in New Zealand. Such an exploration will also elucidate the geographies of organisations associated with diabetes education in New Zealand.

1.4 Thesis Aim and Objectives

The aim of this thesis is to examine the quality and effectiveness of diabetes education in New Zealand. It has two broad research objectives:

1. To investigate the role of and perceptions surrounding the Diabetes Societies in New Zealand, the influence of geographical factors on these perceptions, and to explore people's experiences within this diabetes educational space. This objective encompasses four key research questions:
 - 1.a Who belongs to the diabetes societies and do any trends emerge within membership characteristics, for example in relation to age, sex or type of diabetes.
 - 1b To what extent do members perceive their society as being effective in dealing with increasing rates of diabetes in New Zealand?
 - 1c To what extent are members involved with their diabetes society?
 - 1d To what extent do members prefer their diabetes society as an educational provider?
2. To provide an in-depth exploration of the extent to which diabetes educational services are utilised in the city of Christchurch.

1.5 Thesis Structure

To accomplish these objectives the thesis is organised as follows. Following on from this introductory chapter, Chapter Two begins with an overview of diabetes. It identifies differences between type 1 and type 2 diabetes, addresses the definitional concerns that arise and discusses the role of contextual and compositional factors that are associated with diabetes. It is important to understand how the prevalence of diabetes varies between different places and between different population groups in

relation to the provision of diabetes education and where resources need to be targeted.

Chapter Three introduces a theoretical context to understand the different responses to the global diabetes epidemic and the provision of diabetes care and education. Chapter Three also illustrates the importance of ideologies in shaping these responses. It briefly outlines the role of the medical and social models of health and the role of public health for diabetes. The provision of diabetes care varies between places. Therefore, a discussion of three international examples demonstrate the variations between places in the provision of diabetes care, and the role of ideologies in accounting for some of these variations. A contextual background to the role of geography for understanding regional and organisational variations will also be discussed.

Chapter Four then provides an analysis of diabetes in New Zealand. It discusses the prevalence of diabetes and outlines the structures that are in place to deal with diabetes. A contextual discussion of the role of voluntary organisations in health provides a background for the evolution of Diabetes New Zealand. Examples of programmes that have been implemented to address growing rates of diabetes in New Zealand will also be presented.

Chapter Five outlines the research strategies and methodologies that have been used throughout this research. The chapter begins with a discussion of the questionnaire, how the sample population was selected, the administration of the questionnaire and how the data were analysed. The second part of the chapter discusses the qualitative methodologies that were used in this research project, namely focus groups and interviews.

Chapters Six and Seven introduce the data and present the findings from this research. Chapter Six presents findings in relation to member's perceptions of the diabetes societies. It provides an overview of member's responses and then introduces the differences that arose between rural and urban societies, and between two societies situated within different models of health care organisation. Chapter Six also presents findings from data obtained from Pegasus Health and the Christchurch Diabetes Society, pertaining to people with diabetes in Christchurch. Chapter Seven presents

the findings generated from the in-depth qualitative research. It will discuss several key themes in relation to the utilisation of diabetes educational services in Christchurch.

Chapter Eight analyses and interprets the findings of this research and creates a synthesis between the quantitative and qualitative data. It also situates and interprets the findings within the wider body of relevant literature. Finally, the conclusions of this research are presented in Chapter Nine, leading into a way forward for diabetes by presenting some key policy and theoretical implications emerging from this research. It also highlights ideas for future research in this area.

CHAPTER 2

Nature versus Nurture:

Diabetes and the Role of the Environment

2.1 Introduction

There is a continuing debate over the relative importance of genes and the environment in relation to the aetiology of many health problems, thus the age old 'nature versus nurture debate'. However, it is currently thought that both genetic and environmental factors are important for diabetes, although the interaction between these factors is unclear (Dahlquist et al 1990; Ravussin et al 1994; Dunstan et al 2002; Marx 2002; WHO 2002b; Belchetz and Hammond 2003; Farmer et al 2004). Recently, there has been a renewed interest in the environmental factors involved with diabetes. This chapter will address these environmental factors by discussing them in light of the role of contextual (place-based) factors, and compositional (population-based) factors, and why they are important for diabetes. It is important to explore these environmental factors in relation to health issues such as diabetes as it is the social environment in which health and health behaviours occur (Gesler 1991; 1992). First, however it is necessary to define and provide an overview of diabetes and outline the differences between type 1 and type 2 diabetes.

2.2 What is Diabetes?

According to Mosby's Medical Dictionary (Anderson et al 2002, p511) diabetes is a "complex disorder of carbohydrate, fat and protein metabolism that is primarily a result of a deficiency or complete lack of insulin secretion by the beta cells of the pancreas or resistance to insulin". Diabetes results from an absolute or relative deficiency of the hormone insulin. Insulin enables the body to regulate blood glucose levels and permits the uptake of glucose from the blood stream and transports it to

cells throughout the body. Therefore glucose is the body's predominant source of energy and provides the necessary energy for maintaining homeostasis in several vital processes, for example, regulating body temperature and maintaining and replacing tissue (Brown 1988; Anderson et al 2002; Belchetz and Hammond 2003; Farmer et al 2004).

There are several different definitions of diabetes. Each definition identifies different aspects of diabetes. It is important to acknowledge these different definitions as they may influence the way diabetes is treated by health professionals and perceived by the general public. For example, the World Health Organisation (2002b, p1) defines diabetes as a "chronic disease". Efrat (2003, p39) argues that diabetes is a "multifactorial disease". Hedgman (2001, p14) defines diabetes as a "syndrome" and Brown (1988, p7) states that diabetes is a "metabolic disorder" while the New Zealand Ministry of Health (2004) defines diabetes as a "chronic condition". Differences in defining diabetes also arise between people who have diabetes and the medical professionals, and within medical and health related texts themselves. However, for the purposes of this research diabetes will be defined as a chronic metabolic disorder. Diabetes is classified as chronic because the disorder persists for the remainder of the person's life (Anderson et al 2002). Diabetes is a metabolic disorder as it is associated with problems in the metabolic system, for example, carbohydrate, fat and protein metabolism. It is a disorder because it is "a disruption of or interference with normal functions or established systems" (Anderson et al 2002, p534). To define diabetes as a disease, I believe, has several negative connotations, therefore the term disorder will be used.

2.2.1 Type of Diabetes

There are two main types of diabetes, type 1 and type 2. Type 1 diabetes is an auto-immune² disorder and has an acute onset. Type 2 diabetes is characterised by insulin resistance and has an insidious onset. Fajans (1982) states that diabetes is heterogeneous in its pathogenesis. Type 1 diabetes affects approximately 10% of those with diabetes (Dahlquist et al 1990; Dunstan et al 2002; Marx 2002; MoH 2002c; WHO 2002b; DNZ 2003). The proteins that are found on the surface of many

² Auto-immune disorders and conditions are where the body has set up a reaction to a part of itself (Farmer et al 2004)

cells throughout the body, including pancreatic beta cells, are known as HLA antigens (human leukocyte antigen). The HLA antigens can act as genetic markers to diabetes because the types of HLA antigens people have reflect the genes that are present within the body. They are also responsible for controlling the body's immune responses. HLA antigens reflect the body's ability to fight both bacterial and viral infections. The inheritance of these antigens does not mean that a person will automatically develop type 1 diabetes, rather it serves as a predisposition, increasing the chances of developing type 1 diabetes (Anderson et al 2002; Weets et al 2002; Brown 1988).

According to many researchers exposure to a virus which triggers an autoimmune response is the most likely factor involved with type 1 diabetes (Szopa et al 1993; Seewaldt et al 2000; Rytönen et al 2003; Efrat 2003; Marguerat 2004). Meaning that the pancreatic beta cells, which produce insulin, have been destroyed or fail to produce insulin, this being the central feature in the aetiology of type 1 diabetes (Gepts 1982 cited in Brown 1988). This failure results in the body's inability to handle and metabolise carbohydrates. The auto-immune process occurs over time. So following the initial diagnosis people will still produce some of their own insulin. However, over time, an individual's insulin production will decrease to a point where it is no longer being produced.

At present no cure for type 1 diabetes exists. However, it can be managed with insulin injections (MoH 2002c; Farmer et al 2004). People with type 1 diabetes are dependant on injected insulin for their survival. Blood glucose levels are also monitored by patients with blood glucose meters. It has been postulated by Efrat (2003) that manipulation of the immune system may reduce the susceptibility of the beta-cells to autoimmunity. However, it is currently thought that both genetic and environmental factors lead to the development of type 1 diabetes (Dahlquist et al 1990; Dunstan et al 2002; Marx 2002; WHO 2002b).

Type 2 diabetes affects 80 - 90% of people with diabetes. Although there is no single cause for type 2 diabetes and many factors, genetic and environmental, are involved it is argued that obesity is the most important (Ravussin et al 1994; Belchetz and Hammond 2003; Taylor 2004; Farmer et al 2004). Being obese or overweight, especially abdominal obesity increases, 40 fold, an individual's chance of developing

type 2 diabetes. However, in evolutionary terms storing excess fat would have been advantageous as there were frequent shortages of food. There are also ethnic differences in relation to body weight and the storage of fat (Bhoopatkar and Simmons 1996). However, today food is more available and being able to store fat is not an advantage, and thus levels of obesity are rising. Coupled with a decrease in physical activity the risk of developing type 2 diabetes is increased as insulin can no longer perform its function of breaking down glucose effectively.

The release of fatty acids into circulation is increased as body weight increases, putting an individual at a risk of developing type 2 diabetes. In Type 2 diabetes the body either does not produce enough insulin or the cells in the body do not recognise and respond to the insulin that is produced. Therefore the body is resistant to the actions of insulin (MoH 2002c; Taylor 2004; Farmer et al 2004). Insulin resistance means that insulin is not properly connecting with the receptors, or the receptors are not activating the process to initiate the uptake of glucose. In an attempt to overcome the problem the pancreas responds to the shortage of insulin by producing more, however this increases insulin levels in the blood.

Eventually the pancreatic beta-cells that produce insulin become exhausted and can no longer produce enough insulin. There are currently a range of medications that can improve the pancreas' ability to produce insulin (DiabetesLife 2001; Anderson et al 2002; Farmer et al 2004; Taylor 2004; Mathur 2004). Type 2 diabetes, in some cases, can be managed by having a healthy diet and by increasing physical activity. An increase in physical activity and a reduction in body weight can help the body to decrease insulin resistance, increasing insulin sensitivity.

2.2.2 Definitional Issues

Although type 1 and type 2 diabetes are distinctive in their aetiology there are concerns over how they are defined. It is important to recognise these definitional ambiguities as they may influence the way that diabetes is treated and responded to. Type 1 diabetes has been referred to as 'juvenile onset diabetes', 'insulin-dependent diabetes mellitus (IDDM)', 'ketosis prone diabetes' (Anderson et al 2002; DNZ 2003). However, like the term diabetes, there has been some disagreement over the names and classifications associated with type 1 and type 2 diabetes. Such labels

have now become problematic as type 1 diabetes can be diagnosed at any age and many people who were originally diagnosed with type 2 diabetes are treated with and dependent on insulin injections, commonly associated with type 1 diabetes. The use of insulin is also a way in which type 1 diabetes is classified.

Similar discrepancies exist over classifications for type 2 diabetes. It has been referred to as 'maturity onset diabetes', 'non-insulin-dependent diabetes mellitus (NIDDM)', 'ketosis resistant diabetes' and 'sugar diabetes'. Again such discrepancies arise with these classifications as there is an increasing incidence of type 2 diabetes among youth (Zimmet et al 2003; Young 2004). As mentioned above treatment of type 2 diabetes can involve insulin injections. Furthermore, 'sugar diabetes' associates diabetes solely with sugar, which may lead to misconceptions of diabetes. Such issues make it increasingly difficult for medical and health professionals to classify diabetes as conflicts arise in relation to age and type of treatment. These definitional concerns may also influence the way people think about the severity of diabetes and the implications of the long-term complications that can result.

2.2.3 Why Education Matters: Preventing the Complications of Diabetes

Without insulin, glucose is locked in the bloodstream, elevating blood-glucose levels, and, essentially, starving the body of energy (Brown 1988; Anderson et al 2002; Belchetz and Hammond 2003; Farmer et al 2004). One of the most common acute complications associated with diabetes is hyperglycaemia, it characterised by an elevation of blood-glucose levels. If not managed properly, hyperglycaemia can lead to diabetic ketoacidosis³, which can be life threatening if a person's diabetes is not controlled. Hypoglycaemia, on the other hand, is characterised by low blood-glucose levels. In this case injected insulin has failed to reproduce a physiological insulin profile or a failure of the liver to release glucose. Hypoglycaemia can result in a coma or death if left untreated. The ramifications of uncontrolled hypoglycaemia and hyperglycemias highlight the importance of self-care for diabetes (Anderson et al

³ If hyperglycaemia is left untreated the body can accumulate abnormal amounts of ketones. This accumulation is due to the excessive breakdown of fats caused by a deficiency of carbohydrate metabolism, as free fatty acids are metabolised instead. These free fatty acids are subsequently converted into ketones by the liver, and are accumulated, leading to ketoacidosis, if untreated this process can result in a coma or even death. Ketoacidosis is generally associated with type 1 diabetes, as the destruction of pancreatic beta-cells increases an individual's susceptibility.

2002; Belchetz and Hammond 2003; Farmer et al 2004). The implications of hyperglycaemia and hypoglycaemia illustrate the need for effective and adequate diabetes education is vital to ensure that people with diabetes understand what hypoglycaemia and hyperglycemias are, how they can be affected and how to manage their blood-glucose levels efficiently to avoid complications.

Diabetes can also result in complications with the eyes, kidneys and feet. Diabetic retinopathy (diabetic eye disease) is the one of the most common causes of blindness in people aged between 16 and 64. It is caused by damage and changes to fine blood vessels that supply the retina. Damage to the kidneys, diabetic nephropathy, accounts for a high proportion of end-stage renal failure throughout the world (Belchetz and Hammond 2003). Diabetes can also damage your nerves (neuropathy). The major complication of diabetic neuropathy is foot ulceration. Between 5 and 10% of people with diabetes will experience foot ulcers and 1% will undergo an amputation.

Ischemic heart disease and stroke are frequent causes of mortality and morbidity for people with diabetes. The risk of developing such complications is increased by the presence of hyperglycaemia. Because blood becomes glycaeted and consequently thicker, this can result in blood clots to blood vessels that supply the heart, brain or legs. By maintaining a healthy body weight and exercising regularly the risk of developing these complications can be reduced. However, type 2 diabetes has an insidious onset. As such it may only be initially diagnosed after a heart attack or stroke has occurred, while being present for several years. Therefore the risk of developing heart or blood vessel disease is increased.

Given the significance of the complications that are associated with diabetes it is vital that diabetes itself is prevented to reduce the potential impact, morbidity and mortality. With careful management, from individuals and health professionals, good glycaemic control and on-going education it is possible for complications to be prevented and there impact reduced (Marx 2000; Anderson et al 2002; Belchetz and Hammond 2003; Farmer et al 2004). However, not everyone who has diabetes will develop these complications. There are also variations in the prevalence of diabetes between different places and population groups. Therefore it is important to understand the role of the environment for diabetes and the variations in diabetes rates globally.

2.3 Geographical Variations: The Influence of Context and Composition

The global prevalence of diabetes varies geographically. The distinction between contextual and compositional effects on health is a useful framework for analysing such variations. Contextual effects are related to aspects of places and compositional effects relate to the characteristics of people within certain places. An analysis of contextual and compositional factors allows elements of the social environment to be incorporated. Therefore a more holistic understanding of factors that influence diabetes can be gained (Macintyre et al 2002). Contextual and compositional factors are necessary to understand because they can provide insight into how and where diabetes education and care should be provided to help reduce the impact and incidence of diabetes and increase awareness among specific population groups. This section will address the role of contextual and compositional factors and their importance for diabetes. The contextual factors that will be addressed relate to urbanisation, lifestyle factors, for example, obesity, physical activity, food consumption, migration and cultural change, and the role of the health system. The compositional factors that are important for diabetes are age, gender, socioeconomic status and ethnicity.

2.3.1 The Role of Context

Urbanisation has been identified as a risk factor for an increasing prevalence of diabetes. Although unclear exactly how this relationship operates, it is thought that the diabetes epidemic in some urban areas around the world, for example, in India and Bangladesh, is related to the changes resulting from urbanisation. The changes associated with urbanisation may relate to food consumption or employment patterns. The relevance of urbanisation as a risk factor for diabetes is highlighted by the marked variations in diabetes prevalence between urban and rural areas (Sayeed et al 1997; Ramachandran 1999; Yudkin et al 1999; Abdul-Rahim et al 2001; Williams et al 2001; Diamond 2003). Rural areas of developing countries have a lower diabetes prevalence, whereas urban areas have a much higher prevalence (Yudkin et al 1999; Diamond 2003). Ramachandran et al (1999) found that rural areas in southern India had a prevalence of type 2 diabetes around 2%, while that of urban areas was 11.6%. The lower prevalence in rural areas may be partly related to an under-recording and under-diagnosis of type 2 diabetes. However, urban areas encourage a different

lifestyle from their rural counterparts, potentially influencing a higher incidence of diabetes (Haffner 1998; Abdul-Rahim et al 2001).

There are also geographical variations associated with type 1 diabetes. A study conducted by Cherubini et al (1999) found significant differences in the incidence of childhood type 1 diabetes among different areas of Central-Southern Italy. People living in rural areas had lower rates; the incidence of type 1 diabetes decreased as urbanisation decreased. A higher incidence of type 1 diabetes has also been found in urban areas of Wisconsin in the United States and Novosibirsk in Russia compared to rural areas (Cherubini et al 1999).

Finland has one of the highest incidences of type 1 diabetes in the world. It was found that there is an inverse relationship between the incidence of type 1 diabetes and level of urbanisation Rytönen et al (2003). This inverse relationship is explained by the possibility that some environmental risk factors for type 1 diabetes may be more prevalent in rural areas. Due to the relative homogeneity of the Finnish population it can be assumed that the observed rural/urban differences in the incidence of type 1 diabetes is related to characteristics of the local physical and social environments. However, Rytönen et al (2003) state that levels of urbanisation only partly explain the rural/urban differences that exist. These contrasting findings signify that the relationship between type 1 diabetes and rural and urban environments is unclear.

The inconsistent nature of relationships between the incidence of type 1 diabetes and levels of urbanisation may relate to the different characteristics and classifications 'urban' and 'rural' areas in different parts of Europe (Rytönen 2003). Cherubini et al (1999) attempted to explain some of the differences that occur between rural and urban areas. They hypothesised that urban areas may experience a greater degree of genetic mixing due to migration. In comparison to rural areas where the genetic background of the original population may be increasingly homogeneous and better preserved. In general specificities involved the aetiology of type 1 diabetes are not clearly understood and are harder to ascertain due to the lack of foreseeable modifiable risk factors, unlike type 2 diabetes where there are known modifiable risk factors. Karvonen et al (2000) also raise the issue that the increasing incidence of type 1 diabetes may be related to improvements in case ascertainment, although this

remains unclear. However, an increasingly urban environment may lead to changes in lifestyle, for example obesity, food consumption, and levels of physical activity.

Obesity and decreased physical activity are known risk factors for type 2 diabetes (Sayeed et al 1997; Yudkin et al 1999; Abdul-Rahim et al 2001; Belchetz and Hammond 2003; Gorman 2003; Racette 2003; Farmer et al 2004). Obesity is becoming an increasingly common problem in many places. Racette et al (2003) stated that between 1999 and 2000 an estimated 64.5% of Americans were overweight. This is compared with only 46% being overweight between 1976 and 1980. The USA also has a high prevalence of diabetes. Over the past 40 years the USA has also seen a steady increase in the prevalence of diabetes. This increase has resulted in approximately 10.5 million people being diagnosed with diabetes in 1998⁴. Therefore, obesity cannot be viewed in isolation when analysing diabetes prevalence.

Food consumption patterns must be taken into consideration when analysing the prevalence of diabetes. Changes in food consumption, for example, the abundance of fast food outlets, especially in urban areas, serving foods with a high saturated fat and carbohydrate content may account for the rising incidence of obesity. These lifestyle changes for example, food type and availability, may lead to increasing abdominal obesity and insulin resistance, thus increasing the risk of developing type 2 diabetes (Sayeed et al 1997; Yudkin et al 1999; Abdul-Rahim et al 2001).

Dr Robyn Toomath (2004) asserts that we are now entering the 'age of the sloth'. Toomath asserts that vulnerable groups, for example children are exposed to powerful media images and with the advent of computer new technologies children are becoming increasingly sedentary. Increasingly sedentary lifestyles also can contribute to insulin resistance, coupled with a change in food consumption a general rise in body weight may occur (Belchetz and Hammond 2003; Farmer et al 2004). A more sedentary lifestyle may be more common in increasingly urban environments given the nature of employment, for example, office or factory work.

The case of the Pima Indians of Arizona in the USA exemplifies the importance of lifestyle changes for diabetes. Ravussin et al (1994, p9) state that "change in lifestyle

⁴ Note that approximately 10% of people diagnosed with diabetes have type 1 and approximately 90% of people with diagnosed diabetes have type 2.

is a causal factor of the obesity and NIDDM [type 2 diabetes] epidemic in the Pima community of Arizona". The Pima Indians have one of the highest recorded rates of type 2 diabetes in the world (Ravussin et al 1994; Williams et al 2001; Bunt et al 2003; Belchetz and Hammond 2003; Diamond 2003). Diamond (2003) and Belchetz and Hammond (2003) estimate that the prevalence is approximately 50%. Ravussin et al (1994) concluded that Pima Indians living in North Western Mexico had a remarkably lower prevalence of type 2 diabetes than Pima Indians living in Arizona.

The increase in diabetes prevalence between Pima Indians in North Western Mexico and those living in Arizona illustrates the importance of migration status and cultural change for diabetes rates. The ancestral lands of the Pima Indians were in a remote mountainous location in North West Mexico, varying markedly from the environment in Arizona. The 'traditional' Pima diet predominantly consisted of grains, mesons and legumes, and consisted of higher levels of physical activity. However, upon migration to a new environment in Arizona, which involved adapting to a new 'culture' and lifestyle, the Pima diet and lifestyle changed markedly. The diet of the Pima Indians in Arizona consists of lower levels of physical activity and higher levels of saturated fats, simple carbohydrates and less fibre (Ravussin et al 1994; Williams et al 2001). It is thought that the change in diet, physical activity and overall lifestyle evident between the Pima Indians, due to their migration, may account for marked differences in diabetes prevalence between the Pima Indians in North West Mexico and in Arizona, thus illustrating the importance of contextual factors for diabetes. Migration and cultural change is also an important factor for diabetes rates for Pacific Islanders in New Zealand and will be discussed in Chapter Four.

Another important contextual factor in relation to diabetes is the health system. Health systems are complex and vary immensely between places (Curtis and Taket 1996). Health policy and health care delivery are influenced by the professional and administrative framework within countries, as well as the resources, demographics and epidemiological factors. For example, one contextual factor, hospital bed supply, is significantly related to diabetes hospitalisation, even after controlling for compositional factors (Brown 1988; Brown and Barnett 1992). There may also be factors, inside or outside existing frameworks that affect the nature and structure of health systems (Curtis and Taket 1996; Petersen and Lupton 1996). The structure of national health systems and the overarching ideologies can influence the development,

organisation and culture of the health system and health care delivery. Furthermore, the existing social, political and economic environments influence the development of national health systems. Therefore, the different structure and organisation of health systems that emerge between places can affect the availability of services for people with diabetes. Ideological changes within a country's health system may also influence the availability of services for people with diabetes (Gesler 1991).

2.3.2 The Role of Composition

Examinations of various population groups and compositional factors are necessary to help increase our understandings of the aetiological factors that are involved in diabetes. Compositional factors, such as age, gender, socioeconomic status and ethnicity are important in relation to diabetes. Researchers are increasingly paying more attention to the construct ethnicity in the field of health (Karter 2003). It is important to understand the influence compositional factors on diabetes prevalence. The following section will address the role of these compositional factors for diabetes.

There are variations associated with diabetes in relation to age and gender. Increasing age is a risk factor especially for type 2 diabetes, where the peak age of diagnosis is around 60. However, in 'high risk' populations, the age of onset is significantly lower. According to Wild et al (2004), one of the most significant changes in diabetes prevalence worldwide seems to be the increasing rates of diabetes with increasing age. This is especially true for type 2 diabetes which is often associated with increasing age as a 'mature' pancreas does not work quite as well as a younger one. The over 65 population is predicted to experience the greatest population increase in the next decade (King et al 1998; Belchetz and Hammond 2003; Wild et al 2004). Therefore it is important to ensure that this age group is aware of and receive adequate diabetes education, due to their elevated risk of developing type 2 diabetes, about the strategies that can be undertaken to prevent diagnosis or the development of complications.

Furthermore it has been found that there are more women with diabetes than men (King et al 1998; Wild et al 2004). This trend is especially evident in developed countries where women generally tend to live longer than men and because of this higher rates of diabetes will occur among older women. However, Chan et al (1994)

identified that a high waist to hip ratio was a risk factor for type 2 diabetes. This risk factor was commonly observed among men, who had a large waist circumference due to high levels of abdominal adiposity. However, Chan et al (1994) identify that there is conflicting evidence in relation to the influence of gender for the development of diabetes.

Furthermore, there is a significant relationship between diabetes and socio-economic status. It has been found that, especially in Western countries, type 2 diabetes is more prevalent in lower socioeconomic groups (Haffner 1998; Agardh et al 2004). According to Agardh et al (2004), the relationship between lower socio-economic status was especially significant for non-Hispanic women. This relationship adds another layer to the gender dimension that is associated with diabetes rates.

In the USA the prevalence of diabetes is highest in minority populations (Haffner 1998; Harris 1998; Harris 2001; de Renkneire et al 2003). African Americans, Mexican Americans and Native Americans have a 2, 2.5 and 5 times greater risk of developing diabetes, respectively, than Caucasians. Given that an increased diabetes prevalence among minority groups in the USA has also been accompanied by an increased prevalence of end-stage complications, these groups have been the most severely affected by diabetes. It is also thought that some ethnic groups have a higher concentration of microalbuminuria. Microalbuminuria is a urinary secretion containing small amounts of albumin, a type of protein, which is also an indicator of diabetes (Moore and Lunt 2000; Anderson et al 2002).

The concept of 'thrifty-genes' provides a possible explanation for the higher diabetes prevalence in some ethnic groups. Although a genetic factor the thrifty genotype does not act in isolation from environmental influences. The concept of the thrifty genotype indicates a genetic predisposition to weight gain. This concept may be important in the case of the Pima Indians in Arizona (Ravussin et al 1994). Some ethnic groups have predisposition to store fat and have a higher body mass index. Therefore under certain environmental conditions, for example changes in food consumption, some ethnic groups may have a tendency towards a higher prevalence of obesity and being overweight (Ravussin et al 1994; Marx 2002). This genetic susceptibility increases the risk factors for the development of diabetes among such groups. Therefore, educational strategies to increase awareness and understanding

among these groups are important. The concept of the thrifty genotype also illustrates the interplay between contextual and compositional factors, as exposure to a particular environmental stimulus can then trigger a genetic response, given a predisposition. Therefore, diabetes and analyses of diabetes rates cannot be examined in isolation from contextual and compositional factors.

2.4 Chapter Summary

This chapter has provided an overview and definition of diabetes, discussed the aetiology of both type 1 and type 2 diabetes and the complications that can result. The importance of environmental factors for diabetes has also been explored. It has outlined several key contextual and compositional factors that must be taken into consideration when analysing diabetes rates. The geographical variations, in relation to context and composition that have been presented are important for the identification of at risk areas and at risk groups.

Diabetes is a serious public health issue and WHO (2003) estimate that approximately one in twenty deaths can be attributed to diabetes. In financial terms diabetes can consume up to 15% of annual health budgets. For countries that are already under financial pressure diabetes significantly increases this burden. The following chapter will address how the diabetes epidemic has been responded to at the global level. It illustrates the role of ideologies and institutions in relation to diabetes and illustrates the importance of diabetes education. The importance of a geographical approach to investigating regional differences in health care provision will also be introduced.

CHAPTER 3

Responses to the Diabetes Epidemic: The Provision of Diabetes Care and Education, and the Role of Ideologies

Disease is assigned to the biological realm in Western thought, but humans are social creatures who interact with others to generate explanatory models of their world and to impose order on things and the meaning of the exigencies of life. These processes, including the recognition of and explanations of disease are cultural processes.

Dew and Davis 2005, p87

3.1 Introduction

Many countries now recognise the severity of the diabetes epidemic. The previous chapter discussed the global distribution and geographical variations that are associated with diabetes. However, along with describing diabetes globally it is necessary to analyse how countries have responded to diabetes, and what ideologies have influenced these responses. The aim of this chapter is to investigate the ideologies and systems that have emerged in response to this growing epidemic and to outline how diabetes care and education has been provided in various place in light of these ideologies.

The first section of this chapter discusses the overarching paradigms of health, namely the biomedical and social model of health. These models represent an analytical distinction between medicine and the social sciences. As the boundaries between the two approaches are often blurred it is useful to view them as a continuum. The second section outlines the role of public health, and associated concepts, specifically health promotion. This discussion briefly illustrates how diabetes care and education is provided in three places, the United Kingdom, the USA and Ireland, and explores the way ideologies are reflected in the different responses to diabetes. The third

section will address the role of geography within the context of health and health care. It discusses the importance of geography for understanding regional and other variations in the provision of health care services by the voluntary sector.

3.2 Medical and Social Models of Health

The biomedical perspective of health has been dominant in Western thought especially up until the 1980s. It is important not to isolate the biomedical approach from the wider social and historical context in which it was situated namely Enlightenment science and positivism, both of which influenced biomedicine. Biomedical perspectives are generally linear: a cause is identified, lesions are explored, symptoms are classified and a cure is identified in nature. Quantitative methodologies are used to test hypotheses in an objective manner (Eyles and Woods 1983; Joseph and Phillips 1984; Jones and Moon 1987; Curtis and Taket 1996; Kearns and Moon 2002; Gatrell 2002; Bury and Gabe 2004). The biomedical approach and associated concepts has informed the sub-discipline of medical geography. The biomedical perspective likens the body to a machine, that when broken it is fixable and operates within a highly medicalised discourse (Curtis and Taket 1996; Davis and Dew 1999; Nettleton and Gustafsson 2002). Biomedicine also tends to emphasise physiological abnormalities and attribute the cause of illness to micro-organisms (Kottak 2000; Edgar and Sedgwick 2002 Gatrell 2002). Proponents consider biomedical approaches to be rational, neutral, and detached from the social context, however, the concept and idea of 'place' is neglected by a biomedical approach

Social, lifestyle and environmental factors are neglected by the biomedical approach. The social model of health emerged out of the critique of a biomedical model (Nettleton and Gustafsson 2002). Renè Dubos, a critic of the biomedical perspective, argues that, given the importance of the social environment and the changing nature of our health the biomedical framework is not appropriate. He maintains that there are numerous conditions under which micro-organisms flourish. Methodologies for exploring disease must be rigorous and diverse if they are to cope with emerging diseases and changing approaches to both ill health and health (Dubos cited in Moon and Gillespie 1995). In the case of diabetes, although the medical aspects are important, given the complexity of diabetes it fits poorly into a health care system that

is designed to deal with acute and episodic illnesses, and which predominantly focuses on cures and treatments (MoH 1997; Crawley 1999).

Health cannot be detached from social meaning. The social model or approach to health challenges the dominance of biomedical approaches and incorporates the 'social' (Bury and Gabe 2004). Proponents of the social model argue that a disease cannot always be attributed to one causal factor. They assert that there is an interaction between numerous social, economic or biological factors. The social model of health espouses that health is more than just the absence of disease and a more holistic approach to health is necessary (Kearns 1994). The social model may have influenced the World Health Organisation's definition of health as "a state of complete physical, mental and social well being and not merely an absence of disease or infirmity" (Kearns and Gesler 1998, p9; Gatrell 2002, p4).

An important element of the social model of health is that humans are embodied, they have experiences and as such should be cared for as opposed to 'fixed'. A key component of the social model is the idea that health, disease and illness are not just related to physiological changes but are shaped and influenced by the wider social, economic, cultural and political contexts (Nettleton and Gusfasson 2002). For example, it is known that people who live in more deprived areas are at a higher risk of developing diabetes, and that people from particular ethnic groups are also at a higher risk of developing diabetes, especially type 2 (Haffner 1998; Harris 1998; Harris 2001; de Renkeneire et al 2003). This is what Emile Durkheim has described as the "upstream determinants of health" (Durkheim cited in Bury and Gabe 2004, p100). Durkheim's primary aim was to explain how individual pathology was a function of social dynamics. An increasingly social model encompasses place-sensitive and people-centred analyses focusing on perceptions, views and experiences, thus a more humanistic focus. Greater consideration has been given to people, places and health, and how they interact (Kearns 1994; Kearns and Moon 2002; Nettleton and Gustafsson 2002).

The ways in which health and ill health are thought about and responded to has undergone profound changes. In turn the health policies and the organisation of health care provision within countries have been modified. Public health is an important part within the network of health care provision. However, public health

has also undergone significant changes, affecting the operation, structure and nature of public health responses between countries. Public health means different things in different places. Therefore there are regional and organisational variations in the nature and organisation of public health.

3.3 The Old and New Public Health

The origins of public health can be traced back as far as the ancient Greeks and the Hippocratic School. However, it was during the early nineteenth century that a systematic approach to public health began. The development of the humanitarian ideals and ideas of public virtue initially sparked the dawning of the 'golden age of public health' (Beaglehole and Bonita 1997, p147) or the 'old public health'.

The old public health has been referred to as the "medicinalisation of public health" (Baggott 2000, p31). It gave little concern to the underlying social and economic influences on health and disease (Beaglehole and Bonita 1997). Petersen and Lupton (1996) argue that like scientific medicine the old public health was based on the tenets of classical modernism, drawing on the knowledge from 'experts'. The focus of public health shifted, focusing on routes of disease transmission, rather than emphasising cleaning up cities. Bacteriology was a prominent theme and was the foundation for the "new scientific public health" (Beaglehole and Bonita 1997, p155).

Public health, by definition, involves "collective action to protect and promote health" (Beaglehole and Bonita 1997, p153). However, the extent to which collectivity has been emphasised over individualism has varied spatially and temporally. Until the mid nineteenth century public health efforts were largely the work of voluntary and local governments, and actions were usually in response to a specific epidemic threat, and public health efforts were piecemeal (Beaglehole and Bonita 1997). The late nineteenth century public health movement had a significant impact on the development of public health today.

Situated within a more social model of health, the 'new public health' emerged from the recognition that medical care and medical science, alone, cannot solve health problems (Petersen and Lupton 1996). This recognition was also heightened as

societies began to lose trust in the so called 'technical experts' and the objective basis of scientific knowledge. The new public health is a form of public health that goes beyond the modernist strategies and philosophies of the old public health. It attempts to distance itself from hospital-centred curative models of care and moves towards a more active participatory approach (Petersen and Lupton 1996). Broadly speaking, the new public health involves concepts of prevention at the population level and has a broader focus than the old public health (Petersen and Lupton 1996).

During the twentieth century, the state became increasingly involved in public health. Although the state has ultimate responsibility for public health, the planning and coordination of public health activities has varied between different places and over time. However, in all countries the resources devoted to public health are a tiny fraction of the resources devoted to medical care. In 1974 the Lalonde Report from the Canadian Government expressed an idea which led the "first wave of modern health promotion" (Beaglehole and Bonita 1997, p214). Lalonde argued that environments and lifestyles must be given as much attention as human biology (Lalonde 1974). Resources must be directed towards more positive approaches to health and a greater emphasis put on health education and promotion. The ultimate goal being "not only to add years to our life but life to our years, so that all can enjoy the opportunities offered by increased economic and social justice" (Lalonde 1974, p6).

The prevailing social, economic, political and cultural ideologies operating within a society influence the structure and proceedings of public health systems (Beaglehole and Bonita 1997). Therefore there are many different and contested definitions of public health. In 1923 a definition of public health was proposed by Winslow, a leading American public health theorist. Winslow describes public health as:

"the science and art of preventing disease, prolonging life, and promoting physical health and efficiency through organised community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organisation of medical and nursing services for the early diagnosis and prevention treatment of disease, and the development of the social machinery which will ensure to every individual in the community a

standard of living adequate for the maintenance of health" (Winslow 1923 cited in Beaglehole and Bonita 1997, p146).

Although broad, this definition includes some of the key elements of public health theory and practice, namely early diagnosis and community involvement. In 1987 the Acheson Report produced a definition that was favoured by the United Kingdom and many other countries: *"the art and science of preventing disease, promoting health, and prolonging life through organised efforts of society"* (Acheson 1998 cited in Beaglehole 2003, p2).

According to Beaglehole and Bonita (1997), the definition provided by the Acheson Report is the most appropriate. It encompasses the essential elements of the new public health, for example, a focus on whole populations and prevention. It could be argued that it is contradictory to apply an overly broad definition and minimalist strategies. With an extensive definition that encapsulates so many things public health may be at risk from being a mere collection of ideas that cannot deliver a succinct product (Beaglehole and Bonita 1997; Baggott 2000; Beaglehole 2003). Thus public health may be "everywhere and nowhere" (MacKian et al 2003, p219).

The Lalonde Report and other related documents have not been without their share of critics. They were criticised because of the perceived emphasis on the idea of victim blaming and the lack of acknowledgement for the social and the economic determinants of health (Beaglehole and Bonita 1997; Baggott 2000; Beaglehole 2003). This is surprising given the emphasis on the recognition by the new public health, of need to incorporate elements of the social environment into health and health care. It was also thought that elements of the report were too ambitious and that equity could not be achieved. However, the Lalonde Report has challenged traditional views and received international acclaim. The Lalonde Report is the founding document of health promotion (Health Canada 2002).

The Ottawa Charter for Health Promotion was developed by the World Health Organisation in 1986 (WHO 2004). It arose out of the criticisms of the Lalonde Report, and has been referred to by Beaglehole and Bonita (1997, p215) as the "second wave of modern health promotion". It positions health within the socio-political arena and emphasises the importance of social and political elements as well

as the importance of lifestyle and environmental influences on health (Beaglehole and Bonita 1997; Davis and Dew 1999). It aims to encourage mediation between groups to ensure the pursuit of good health (Tones and Green 2004; WHO 2004). In addition the charter states that health promotion should go beyond health and healthy lifestyles and deal with well being. Therefore, the responsibility for this stretches further than the health sector alone (WHO 2004).

3.4 Towards a New Public Health: Health Promotion

Health promotion and its associated principles could be seen as a defining feature of the new public health perspective (Downie et al 1996; Griffiths and Hunter 1999). The concept of health promotion is often contested and means different things to various people and in different places (Tones and Green 2004). It has been defined as “a strategy for promoting the health of whole populations” (Bunton and MacDonald 2002, p10). Defined by the Ottawa Charter, health promotion is “the process of enabling people to increase control over, and to improve their health” (Bunton and MacDonald 2002, p102; WHO 2004). Health promotion could also be seen as advocating for structural changes to the social, political and public health networks of society. To summarise a much quoted formulae (Bunton and MacDonald 2002, p103; Tones and Green 2004, p14): “Health promotion = health education + healthy public policy”. Health promotion is one way in which medicine has been brought out of the clinical environment and into homes and communities.

Health Promotion involves two integral ideas: empowerment and education (Bunton and MacDonald 2002; Tones and Green 2004). The notion of empowerment originated from community development programmes during the 1970's. The empowerment philosophy has been revitalised since the retreat from neoliberal ideologies. It involves the distribution of power and argues that all people who are involved in a process, especially the beneficiaries, should be active participants and involved in decision making. Thus there is an increasing emphasis placed on government-community partnerships. The goal is to produce behaviour in a specific direction rather than imposing a state of perfect health. Empowerment can be related to individuals or communities, working with people to build trust, mutual respect and a supportive environment (Bunton and MacDonald 2002; Tones and Green 2004).

Education is also vital for empowerment. Health education embraces a social approach. It attempts to influence attitudes, increase knowledge and to encourage learning and participation. Enabling people to make informed decisions their diabetes, for example, is crucial to the notion of education within health promotion. Such approaches are ultimately aimed at stimulating a healthy environment by taking into account the social, economic and cultural context of individuals and communities. Health education should be viewed as a process not just a mere presentation of facts (Bunton and MacDonald 2002; Tones and Green 2004).

3.5 Diabetes Care and Education

The pervasiveness of the ideologies surrounding public health and the resulting institutions have had a key role in shaping the way diabetes and the diabetes epidemic has been responded to, both at the global and local scale. There are a number of known modifiable risk factors, especially in relation to type 2 diabetes, for example diet and physical activity. Therefore, in some cases it is theoretically possible to prevent the development of type 2 diabetes. Prevention and intervention can occur at different levels, namely, primary, secondary and tertiary.

Primary prevention pertains to interventions which attempt to prevent diabetes from developing in susceptible individuals or populations (Lindsay 1999). This may be achieved by reducing behavioural and environmental risk factors, for example, increasing physical activity, for the entire population, or specifically those deemed to be at a high risk of developing diabetes. However, primary prevention differs from primary care. Primary care incorporates elements of primary prevention, but generally involves caring for those with diabetes and those at high risk.

Secondary prevention relates to activities such as screening, for example, retinal screening in the case of diabetes. This process attempts to identify undiagnosed cases, resulting in early intervention. It also involves preventing deterioration and the development of complications among those already diagnosed. Tertiary prevention involves strategies to reduce and mitigate diabetes related complications such as lower limb amputation and renal failure (Curtis and Taket 1996; Lindsay 1999).

Primary care, on the other hand, is usually administered in a medical clinic or health centre or in the home and encompasses a range of preventative strategies. The movement towards a more primary care orientated health system is espoused in much of the literature (Carpenter 1999; Crawley 1999; Lindsay 1999; Waine 1999; Hughes 1999; WHO 2003). Secondary and tertiary care are also important for people with diabetes. Secondary care is predominantly offered in a hospital setting. Patients are admitted for treatment that cannot be received in a health centre. Patients may be referred to a specialist for further investigation or surgery. Smaller hospitals may not have access to such facilities and would then be referred to tertiary care settings elsewhere for further specialist care. In the case of diabetes this may be a diabetes centre (Curtis and Taket 1996; Gatrell 2002). Many authors argue that a primary care environment encapsulating primary prevention and the development of supportive environments is vital to ensure movement towards preventative health strategies, which incorporate education (Carpenter 1999; Crawley 1999; Waine 1999; Hughes 1999; WHO 2003). It is argued that, in the long term this will significantly improve diabetes care, and help to reduce the burden of diabetes (Crawley 1999).

Diabetes education is a vital component of diabetes care and management. Education is a readily modifiable social determinant of health (Beaglehole and Bonita 1997). Education involves the acquisition of information which enables people to engage with information in a way that benefits their health. A clarification and reinforcement of existing values and the development of new values and ideas may also result. For example these could include new ideas about nutrition and diabetes resulting from a visit to a dietician or reading a new book and subsequently making informed decisions about dietary choices. There is a strong emphasis on self care and empowerment. However, it could be argued that notions of self care may contradict the principles of the new public health, as it neglects ideas of community and social support for health, thus a balance needs to be obtained (Petersen and Lupton 1996). A platform for the adoption of healthy public policies must also be established (Tones and Green 2004). However, exactly how this platform and balance are to be achieved and established is not outlined in the literature.

Ideas of health, health policy and health care delivery are never developed in isolation (Curtis and Taket 1996; Petersen and Lupton 1996). National health care systems are also influenced by the political structure and framework within countries. There may also be factors inside or outside existing frameworks influencing the structure of

health care provision. There is no single solution for achieving universal health care for a population. Health systems are complex and vary immensely between countries (Curtis and Taket 1996).

3.6 International Examples

This section outlines examples, from the United Kingdom, the USA and Ireland to illustrate how various countries have responded to the diabetes epidemic and how diabetes care and education is provided. An analysis of how various health care systems provide diabetes care and education illustrates the role of ideologies in the development of health care structures. These examples will give an insight to what extent different health systems incorporate the concepts of health promotion, whether there has been any significant movement towards primary care, which is espoused in much of the public health literature. These examples will also illustrate how the existing social, political and economic environments influence the development of national health systems.

3.6.1 Diabetes Care in the United Kingdom

In the United Kingdom the overarching ideology is fundamentally 'collectivist'. Established in 1948, the National Health Service (NHS) provided a framework for health care provision on the basis of need rather than the ability to pay. It is funded through both general taxation and taxes on those in employment. The state controls resource distribution (Tripp 1981; Mohan 1995; Curtis and Taket 1996; Gatrell 2002). The public sector is predominantly responsible for the provision of services.

However, it was not until the acceptance of the Saint Vincent Declaration⁵ that the relatively low priority given to diabetes was addressed. The Saint Vincent Declaration has also had a strong influence for the provision of diabetes care and

⁵ In 1989 the Saint Vincent Declaration was accepted at the 1st meeting of The Saint Vincent Declaration Diabetes Action Programme, Saint Vincent, Italy, by Representatives of Government Health Departments and patients organisations from all European countries. In 1999 the Istanbul Commitment was also unanimously adopted at the 10th anniversary meeting of The Saint Vincent Declaration Diabetes Action Programme (International Diabetes Federation (IDF) 2003). Several goals and targets were described by both declarations. Both documents have become real concepts in the world of diabetes at global and national levels.

education in the United Kingdom. In 2003 it was recognised by the International Diabetes Federation (IDF) that, although still important, the goals of the Saint Vincent Declaration were either not reached or alternative avenues had not been explored.

Emerging from this recognition was the call for a more “primary care led” health system and a focus on diabetes (Gatrell 2002, p140; IDF 2003a; Primary Care Diabetes (PCD) Europe 2004). Therefore, in 2001 diabetes was the fourth area of health care to be the subject of a National Service Framework (NSF) (Carpenter 1999; Pringle 2000; Rodgers 2000; Department of Health 2004). The NSF aims to improve the overall quality of diabetes services in England and Wales as well as prevent the incidence and burden of type 1 and type 2 diabetes (Rodgers 2000; Department of Health 2004). Central to the NSF framework is the role of primary care and primary care trusts (PCTs) for diabetes (Department of Health 2002). The importance of the ‘local’ is emphasised throughout the policy documents (Department of Health 2004).

Under the NSF Delivery Strategy (Department of Health 2003) emphasises the need for collaboration between local, national and regional, as well as between the different stakeholder groups. However, it is not clear from these documents exactly how this collaboration should occur. An increasingly bottom up approach to diabetes care is adopted. This approach and the emphasis on the ‘local’ and collaboration may be influenced by ideologies and concepts from health promotion and public health. At the outset these strategies adhere to many public health concepts and ideals. However, whether they are more than political rhetoric remains to be seen.

3.6.2 Diabetes Care in the United States of America

In contrast to the United Kingdom The USA has a predominantly ‘anti-collectivist’ health system. The nature of the American health system may reflect a more individualistic society, due to ideologies such as neoliberalism (Curtis and Taket 1996). Funding generally comes from private health care insurance schemes. Independent providers, with a small input from the public sector, are the dominant sector responsible for the provision of services (Curtis and Taket 1996). The insurance schemes are often arranged by the individual and tied to employment. There are also two state schemes: Medicare and Medicaid. Medicare covers people aged over 65 years and Medicaid, introduced in 1965, provides partial cover for

people on a low income and offers extremely limited benefits. However, approximately 33 million Americans remain uninsured (Tripp 1981; Gatrell 2002). The burgeoning costs of this provision and insurance schemes along with the inequities in health care provision led to the establishment of health maintenance organisations (HMOs), a form of managed care (Coddington et al 2000; Gatrell 2002). Managed care pertains to the combining of the delivery and financing elements of health care.

Despite the large expenditure on health huge disparities exist within the United States health system, as there is a high proportion of Americans who are uninsured (Curtis and Taket 1996; Coddington et al 2000). A number of people do not receive care from private physicians and are denied appropriate treatment due to their uninsured status. Thus the health care system fails to reach hard-to-reach groups and fails to address the underlying issues involved with ill health, namely deprivation. It is known that there is an association between deprivation and the incidence of diabetes. Those who are uninsured may not have ready access to such care, increasing the burden of diabetes within this population group.

Public health has continually been marginal and neglected in the USA. This influences the way diabetes care and education is provided and what concepts are emphasised in policy documents and declarations. Beaglehole and Bonita (1997) assert that public health will continue to be neglected, both financially and ideologically, until an equitable health care system is established. The Republican Party, for example, tends to emphasise the importance of individual responsibility for public health and as such decrease funding in this area. The nature of resource distribution by the Republican Party illustrates the role of ideologies in the organisation and structure of health care services. Therefore, the organisation of health care cannot be isolated from the political, social, economic and cultural context of a society, at the Federal and State levels. The current emphasis on a more biomedical model may influence the available funding for services such as public health (Coddington et al 2000).

The emphasis on the 'medical' can be highlighted by the slogan of the American Diabetes Association (ADA), which reads: "American Diabetes Association – cure, care, commitment" (ADA 2004). At present there is no known cure for diabetes. It could be argued, therefore, that an emphasis on 'cure' reflects a dominance of the

medical model of health. In contrast to the United Kingdom, words like 'local' and 'partnership' are not as prominent throughout the American literature.

3.6.3 Diabetes Care in Ireland

Diabetes care and education in Ireland, in contrast to both the United Kingdom and the USA is commonly based in secondary care. Some places in Ireland have little or no organised diabetes services (O'Sullivan 2000). Health services are organised into tiers, which may neglect primary diabetes care. Furthermore, O'Sullivan (2000) reports that Ireland has no coherent diabetes strategy and only recently the government has addressed the issues outlined in the Saint Vincent Declaration report. A medical culture of infrequent clinical audit prevails and diabetes services are generally administered in hospital outpatient facilities, excluding general practice. There is no incentive for general practitioners to take on diabetes care and the associated workload. The lack of state support and availability of nursing and other staff ultimately leads to infrastructural limitations for the development of new diabetes care and educational services. The fragmentation of diabetes care in Ireland may reflect the fragmentation of the health system more generally or the political environment.

However, recently there have been rapid developments within diabetes care driven by both local and national inspirations. The Irish College of General Practitioners (ICGP) recently established a diabetes task group. This led to the development of practical guidelines and protocols, national workshops, and upskilling for general practitioners. The ICGP emphasises the need for primary care and highlights its important role for achieving better diabetes care and management. The importance of primary care is also a recurring theme throughout the public health literature. Recognition of a health problem, like diabetes, by the health policy makers, is an important step in order to begin to develop strategies and implement structures to improve the health of the population (O'Sullivan 2000).

These three examples illustrate the differences that arise in the provision of diabetes care and education between countries. It is evident from these examples that different countries incorporate various public health concepts which then shape the nature of

health service provision. Furthermore, how the existing social, political and economic context influences the development of national health systems is demonstrated through these examples. In the case of the United Kingdom it is evident that structure and agency for both important for health care delivery, as frameworks are developed within the national health structure and implemented at the local level which involves local leadership and action. However, as well as variations between countries there are also variations within countries, in relation to health services. Regional variations exist in relation to the evolution of health service organisations, for example voluntary organisations and geography has an important role in understanding these variations.

3.7 The Importance of Geography for Understanding Local and Organisational Differences in Health Services

Regional differences in the provision of health care services exist, especially in relation to the voluntary sector. The structure of the national health system and ideologies can influence the provision of health services at the local level. However, local agency in the development of health services is also an important contributing factor. This section will outline the importance of a geographical approach for understanding local variations in health services and discuss variations associated with development of the voluntary sector. However, it is first necessary to briefly define the voluntary sector.

The voluntary sector operates outside the public, state and private/market sphere. According to Wilson (2001), there is a lack of clarity surrounding the terminology and definitions of the voluntary sector. It has been described as: 'the community sector', 'the third sector', the 'non-government sector', 'the charitable sector' and 'the not-for-profit sector'. However, according to Johnston et al (2001, p739) the voluntary sector is a:

"Shadow state: a para-state apparatus comprised of voluntary non-profit organisations providing a variety of collective goods and services...administered outside traditional democratic politics or avenues of accountability".

Milligan (2001, p113) characterises voluntary organisations as “self-governing associations of people who have joined together to take action for public benefit. They are not created by statute, or established or for financial gain”. Voluntary organisations are not homogenous. There is great diversity in size, structure, funding and services of voluntary organisations, which may contribute to the variety of surrounding terms and definitions (Milligan 2001; Wilson 2001).

Wolch (1990) argues that the development of the voluntary sector is uneven. Two key components resulting in local variations in voluntary organisations are: the basic characteristics of urban economies, government and charity, and the behavioural responses to the local market and state. The outcome of these interactions is the uneven development of the voluntary sector over time and space. Milligan and Fyfe (2004) identify that the uneven development of voluntary organisations leads to, not only uneven access to voluntary services, but also uneven opportunities to participate and be involved in the voluntary organisations. Therefore, regional differences in health service provision by the voluntary sector remain important. Responses to the diabetes epidemic are often developed by voluntary agencies, due to a lack of state intervention or recognition of the importance of diabetes. However, given their status as voluntary organisations their distribution has been uneven (Wolch 1990; Barnett and Barnett 2003; 2004).

National policies intersect and interact with regional and local contexts which may lead to a restructuring of the practices and outcomes of voluntary services. For example, the organisation of health care as centralised or decentralised may affect the nature service provision by the volunteer sector. Hurley et al (1995) argue that decentralised structures operate with more efficiency, which may encourage voluntary organisations to develop due to the community focus of a more decentralised structure (Hurley et al 1995).

“The political economic context of markets, the state and charity sectors shape the dimensions of voluntarism and the trajectory of voluntary sector development over time and space” (Wolch 1990, p115). Therefore voluntary organisations vary between places as a result of state restructuring programs (Black 2000; Milligan and Fyfe 2004). During the 1980s and 1990s there was a move by Conservative Governments towards market-based approaches to local welfare service delivery. It is

interesting to note that the move by the 'New Right' encouraged self reliance however many voluntary organisations still relied on the state for funding. This move encouraged local communities to take increased responsibility and become 'active citizens' for the provision of services which reflected their needs (Milligan and Fyfe 2004). The voluntary sector then has a key role in the provision of health care services for local communities (Wolch 1990; Milligan 2001). The voluntary sector in the USA and elsewhere, for example the UK, gained resources and political influence by becoming a shadow state apparatus, but are increasingly subject to state regulation. However, the role and operation of voluntary organisations are affected by the nature welfare provision and funding at the regional level. Therefore patterns of metropolitan voluntarism vary over space and time.

The relationship between the New Zealand government and voluntary organisations has been maintained largely through the contracting process. Contract arrangements between voluntary organisations have been with health purchasers, rather than the Ministry of health, through the four Regional Health Authorities (1993-1997), the Health Funding Authority (1997-2000) and from 2001 with the 21 District Health Boards (Barnett and Barnett 2004). It was revealed that the four RHA purchasers differed markedly in their contracting styles and relationships with voluntary organisations. In relation to the mental health sector, Newberry and Barnett (2001) identified five characteristics for a successful contractual arrangement between the RHAs and voluntary organisations, they were: effective communication and consultation, timeliness, a coherent approach, appropriate use of power and fostering a mutualist culture. It was identified by voluntary organisations within the mental health sector that these criteria were only met by one RHA. The variations between RHAs resulted in the uneven development of voluntary services due to differences at the regional level in nature of contracting processes (Newberry and Barnett 2001; Barnett and Barnett 2004).

With respect to agency, it is evident that local human actions are an important element involved with variations in the development of voluntary organisations. In response to hospital closure and a rationalising of rural health services in New Zealand, due to market-led reforms, nine rural health trusts were established in Southern New Zealand. However, there has been variability in the outcome and success of these health trusts and in some areas health trusts were not established at all. What is

interesting in the context of the health trusts in Southern New Zealand is that they all developed within the same political and economic climate, the withdrawal of funding and declining rural economies, they were also affected by state restructuring.

Barnett and Barnett (2003) found that local community leadership and capability, the role of local professionals, local legitimacy and trust were critical factors in the success and outcomes of the health trusts. It was also found that there were complex social forces operating within local environments which may account for some of this uneven development (Wolch 1990; Barnett and Barnett 2003).

Milligan and Fyfe (2004) identify that the provision of voluntary services must be in tune with local needs. Voluntary services have an important role to keep in touch with local views and needs. It is vital that members of voluntary organisations have a detailed understanding of the communities in which they serve (Milligan and Fyfe 2004). For example, the development of community health trusts in rural areas may relate to the isolation of rural communities from other health providers. Therefore a community need for health care, following the state withdrawal due to restructuring, was identified and responded to by rural communities. It is argued that local involvement and ownership of voluntary services helps to increase the harmonisation of service delivery and the quality of services for service users, as those in management positions are more in touch with local needs. However, this re-organisation has not been without conflicts (Milligan and Fyfe 2004).

Barnett and Barnett (2003) state that the re-emergence of voluntarism, in the form of community health trusts in rural New Zealand, has heralded a return to the decentralised, community-orientated, patterns of health services provision. Decentralised health service provision has influenced the geography of hospital services in New Zealand. There has been considerable diversity in patterns of provision and much of this diversity is related to the way in which localities have responded to changes in the national health structure (Barnett and Barnett 2003). These examples illustrate that structure cannot be isolated from culture and agency in relation to health service provision by the voluntary sector. Gesler and Kearns (2002) assert that both structuralist and humanist approaches are useful tools for analysing health care in places, and this is true in relation to the regional differences that emerge in the voluntary sector.

3.7 Chapter Summary

This chapter has outlined responses to the diabetes epidemic, globally, and the role of ideologies in informing these responses. It has also presented examples of the provision of diabetes care in three countries to highlight how different countries have responded to the diabetes epidemic and the role of ideologies in shaping these responses. Responses to diabetes are also influenced by national political, economic ideologies and contexts. However, there are also local and regional variations in the development of health care provision by the voluntary sector. Geography has an important role for investigating such variations. The last section of this chapter outlined the role of geography for understanding variations in the development of health service organisations, specifically voluntary organisations. The following chapter will address the issue of diabetes in New Zealand. It will outline the incidence of diabetes and the associated geographical differences and, in light of the conceptual and theoretical insights in this chapter, it will discuss how New Zealand has responded to the diabetes epidemic and the importance of the voluntary sector.

CHAPTER 4

Diabetes and Diabetes Education in New Zealand

4.1 Introduction

The previous two chapters have provided a global context to the issue of diabetes. Chapter Two illustrated the global prevalence of diabetes and the geographical variations that are associated with diabetes. Chapter Three outlined how the diabetes epidemic has been responded to and what ideologies have informed these responses. This chapter situates New Zealand as part of this global diabetes epidemic. New Zealand has experienced similar trends in relation to increasing rates of diabetes. However, interesting trends emerge in diabetes among high risk groups, specifically Maori and Pacific Islanders. As in Chapter Two, compositional or population characteristics, such as ethnicity, age and sex, and contextual or place-based factors such as, urbanisation, deprivation and the health system are an important way of exploring variations in diabetes rates. The first part of this chapter will explore the compositional and contextual factors that are important for diabetes in New Zealand. The second part addresses how New Zealand has responded to the diabetes epidemic and illustrates the role of the health system and health system restructuring. It also discusses the role of the voluntary sector within the context of health care restructuring. Finally this chapter will present two examples of diabetes preventative and educational initiatives in New Zealand, which illustrate the role of the current health system and how ideological concepts are incorporated at the local level.

4.2 A Diabetes Epidemic in New Zealand

It is known that diabetes is a serious and burgeoning problem in New Zealand. Diabetes has been identified as a health priority area. It is also one of 13 population health objectives outlined in the New Zealand Health Strategy 2000 (Health Funding Authority (HFA) 2000; MoH and NZ guidelines group 2003; MoH 2004). In 2001, the Ministry of Health estimated that around 115,000 people had diabetes. The Ministry of Health also predicted that the incidence of diabetes is likely to increase by

two-thirds from 1996 to 2011 (MoH 1999; 2002a; 2002b; 2002c; 2003). It is also estimated that a further 60,000 people have diabetes but remain undiagnosed. The Ministry of Health suggest that these are conservative estimates (MoH 1999; 2002a; 2002c). The estimated increase in diabetes rates will result in a huge burden on society, both socially and economically.

In 1998/99 5% of the total inpatient costs were the primary result of diabetes, equating to approximately \$80 million annually (HFA 2000). Although the 'real' cost of diabetes is unknown, it was estimated that for 1998/99 the cost diabetes and diabetes related complications was \$160 million. However, this is significantly lower than estimated by other health researchers. For example, for 1996 the direct health care costs of diabetes were between \$250 and \$600 million (Simmons 1996a). These figures are likely to increase given the rising prevalence of diabetes in New Zealand (Price Waterhouse Coopers (PWC) 2001; DNZ 2003). Although there is an immense economic burden associated with diabetes, these estimates do not account for the social, emotional and psychological burden that people with diabetes and their families' experience (Summers and Hayes 2001). Such burdens may not be able to be quantified.

It is predicted that the non-fatal burden of diabetes will increase dramatically in the next decade (MoH 2002a; 2002b). The majority of the burden of diabetes in New Zealand relates to type 2 diabetes (HFA 2000). During 2000/2001 3774 people were admitted for diabetes⁶ and diabetes-related problems (New Zealand Health Information Service (NZHIS) 2002). Given the ageing population in New Zealand and the association of type 2 diabetes with older age, this presents a serious public health problem. However, diabetes is often a secondary factor in many hospital admissions, therefore it may not be recorded accurately (Chen et al 2004).

Discrepancies with mortality data have been found, which may influence the validity of diabetes-related statistics. According to Chen et al (2004) clinically documented diabetes is under-reported on death certificates in Christchurch hospitals. A retrospective review of death certificates in 1999 revealed that of the 496 subjects without documented diabetes 32% (159) had a random plasma glucose of

⁶ These figures were taken from the provisional data from the NZHIS, selected diseases, inpatients treated in publicly funded hospitals and means length of stay during 2000/01.

>11.1mmol/l, suggesting diabetes. A healthy range for blood glucose is between 4 - 7 mmol/ (Farmer et al 2004). A further 47% (233) had a random plasma glucose in the range of 7.8 - 11.0 mmol/l. The study concluded that in Christchurch diabetes is under-reported on half of all death certificates. Such findings are significant in relation to health service planning, especially given that in some cases mortality and morbidity associated with diabetes may be able to be prevented through early intervention, prevention and education. However, controversy surrounds whether diabetes itself directly contributes to death (Chen et al 2004). Furthermore, Chen et al (2004) assert that junior doctors must be trained and made aware of this issue and it is vital for more efficient linkages to be established between the New Zealand Health Information Service (NZHIS) and hospital providers.

4.3 Compositional Factors in New Zealand

There are marked variations in the prevalence of diabetes between different groups of the New Zealand population. One significant difference is related to ethnicity. Ethnicity is an important population characteristic that needs to be considered in relation to diabetes in New Zealand. However, age and gender are also important compositional factors that must be taken into consideration. The following section addresses these compositional factors in the New Zealand context.

A study carried out in inner urban South Auckland between 1992 and 1995, revealed that the prevalence of known diabetes was highest among Maori (5.2%) and Pacific Island people (4.0%) (Lindsay 1999). The average annual rate of increase (percent) from 1996 to 2011 is expected to be the highest among Maori and Pacific Island peoples, 13.4% and 14.6% respectively, compared with a increase of 10.4% for the European population (MoH 2002c). Maori and Pacific Islanders also have an earlier age of onset than Europeans (Simmons 1996b). Although there are limited statistics relating to the prevalence of diabetes among the Asian population in New Zealand, the 'other' group, which includes Asians, had a diabetes prevalence of 4.0%, which was still higher than the prevalence rate for Europeans (MoH 1999). Diabetes New Zealand also identify people of Asian origin to be an at risk group (DNZ 2003).

Maori and Pacific Island women have a higher risk of developing diabetes than Maori and Pacific men. However, European men have a slightly higher risk of developing diabetes than European women (MoH 2002c). These differences may relate to poorer glycaemic control among certain groups of the population, indicating a difference in population composition (Moore and Lunt 2000). Maori and Pacific Island peoples also have a higher prevalence of microalbuminuria, an indicator of diabetes, and impaired glucose tolerance than Europeans. In addition, serum uric acid concentrations tend to be higher in Polynesians than Caucasians (Stanhope and Prior 1980). These differences may account for some of the variations in diabetes prevalence within New Zealand (Simmons 1996a).

There are variations in the prevalence of diabetes-attributable morbidity and mortality within the New Zealand population. In 1996, the diabetes-attributable mortality rate (per 100,000) for Maori and Pacific Islanders was 331 and 238, respectively, compared with only 45 for Europeans. Therefore, Maori and Pacific Islanders are five times more likely to die from diabetes than Europeans (MoH 2002a; 2002c). Maori and Pacific Islanders also tend to develop a greater number of complications such as, problems with the eyes, kidneys and feet (Moore and Lunt 2000; Belchetz and Hammond 2003). Pacific Island people, in proportion to the number of people with diabetes, had a higher hospital admission rate compared with Maori and other population groups (HFA 2000). This higher rate of hospital admission may be related to the higher prevalence rate of diabetes among Maori and Pacific Islanders compared to Europeans. It may also be related to differences in the acquisition of diabetes education among different ethnic groups.

Differences in the utilisation of education may create inequalities in health status within New Zealand, which has implications for the targeting of health resources. Furthermore, Maori and Pacific Island people are relatively socio-economically disadvantaged in comparison to other groups (Davis and Dew 1999; Moore and Lunt 2000). The Ministry of Health (1999) also identified that rates of diabetes increased as family income decreased. This trend indicates that deprivation may be associated with increased diabetes rates. A lower individual or family income may result in less money being available for preventative health care and nutritional foods. Therefore the symptoms of diabetes may go unchecked.

In the future, diabetes rates in New Zealand are likely to increase, in response to an ageing and growing population (Brown and Barnett 1992; Simmons 1996a). Given the increasing advances in medical technology people are living longer, contributing to the ageing population. Belchetz and Hammond (2003) assert that with increasing age, males tend to put on weight around their abdomen. Abdominal adiposity is a risk factor for type 2 diabetes. This tendency may account for more males having diabetes than females in New Zealand (MoH 1999). The difference in diabetes rates between males and females raises an important gender dimension especially in relation to the utilisation of diabetes education.

Maori and Pacific Island peoples are more likely to be obese than any other group in New Zealand. Obesity has been identified as a risk factor for the rising rates of diabetes, particularly for type 2 diabetes (MoH 2003). As outlined in Chapter Two certain populations are genetically predisposed to gain weight and store fat easily, reflecting a potential predisposition to developing type 2 diabetes (Simmons et al 1999a; Moore and Lunt 2000). Although the specificities of the genetic processes involved are not fully understood, it is thought that genetic factors shape the individual genotypes which may influence a predisposition towards diabetes, given exposure to specific environmental stimuli.

4.4 Contextual Factors in New Zealand

Although compositional factors, such as age, ethnicity and sex, are extremely important for exploring diabetes rates, a number of studies have illustrated the importance of contextual/place-based explanations of variations in diabetes rates (Stanhope and Prior 1980; Simmons 1996a; Davis and Dew 1999; Moore and Lunt 2000; Schaaf 2000; Willis et al 2000; Canterbury District Health Board (CDHB) 2003). This section will outline contextual factors involved with diabetes in New Zealand namely, urbanisation, deprivation and the health system, which will also be discussed section 4.5.1.

During the 1960s and 1970s the Tokelau Island Migrant Study was undertaken by Stanhope and Prior (1980). This pioneering research revealed that Tokelauans showed a marked increase in prevalence and incidence of diabetes after migrating

from rural areas in Tokelau to more urban areas in New Zealand. This was especially significant among females, as the diabetes prevalence rose from 6.1% before migration to 10.8% after migration. Migrants who had been in New Zealand for a longer period of time also had a higher incidence than newer immigrants. A marked increase in body weight and adipose tissue occurred in migrants, both of which are risk factors associated with type 2 diabetes.

In addition to a shift from a rural to an urban environment cultural change is an important part of this migratory process. Following migration Tokelauans had to adapt to a new culture and way of life. There was also a shift from a rural to a more urbanised environment. Therefore the new urban environment in New Zealand and culture is markedly different in comparison to rural areas in Tokelau. Increasingly urbanised environments may also give rise to different lifestyles, leading to obesity and diabetes (Stanhope and Prior 1980; Moore and Lunt 2000). In New Zealand Tokelauan people's energy expenditure and food consumption changed. Work patterns became increasingly sedentary. Changes in work patterns may be due to the different nature of employment between New Zealand and Tokelau. Employment in urban areas may be based around factory or office work, which is of a more sedentary nature. Food consumption also changed, there was a move away from a more 'traditional' diet, based on high fat, from coconuts, and high fibre, to a diet that consisted of a low fat content, high complex carbohydrates and simple sugars and a greater alcohol intake (Stanhope and Prior 1980). The increase of adiposity in migrants, but not in non-migrants, suggests an interaction between environmental and genetic factors, which highlights the complex nature of diabetes and its development (Stanhope and Prior 1980; Schaaf 2000; Moore and Lunt 2000; Simmons 1996a).

People who live in more deprived areas tend to have higher rates of diabetes (MoH 1999; Evans et al 2000). For example, areas with a higher deprivation decile have a greater prevalence of diabetes compared to areas with a lower deprivation decile ($p = < 0.01^7$) (MoH 1999). Low income environments may influence individual lifestyle choices and health behaviours (Davis and Dew 1999). Moore and Lunt (2000) suggest that, in New Zealand, Maori and Pacific Islanders may receive less than optimal diabetes care due to their socio-economic status.

⁷ This figure is reported in *Taking the pulse the 1996/97 New Zealand health survey*, Ministry of Health, 1999.

However, previous research indicates that there are marked disparities in access to specialist diabetes education and clinical outpatient services by patient age, duration of diabetes and attendance on primary care in Canterbury, New Zealand after controlling for socio-demographic characteristics (Brown 1998; Brown and Barnett 1992). Brown and Barnett (1992) found that diabetes-related hospitalisation had more to do with the availability of medical resources in the area than individual patient socioeconomic status. Rates of diabetes hospitalisation were significantly influenced by resource factors even after controlling for socio-demographic status, thus rates of diabetes hospitalisation are influenced by the availability of medical resources in the area. The presence of an above average supply of general practitioners and specialist ambulatory services in Canterbury were not found to be a deterrent to hospitalisation as considerable variations exist in admission practices (Brown and Barnett 1992).

An exploration of place-based characteristics is important in relation to access to health care services and access to diabetes education. Lack of access to diabetes education may result in a decreased awareness and understanding of the risk factors associated with diabetes. Contextual effects, which may relate to material infrastructure, employment characteristics and social networks, illustrate the importance of the local social and physical environments that may promote or inhibit health and health-related behaviours (Macintyre et al 2002). As such contextual factors must be taken into consideration when exploring diabetes rates. Place-based and population characteristics are important for diabetes rates. It could therefore be argued that health resources should target 'people' and 'places' (Barnett 2000).

4.5 New Zealand's Responses to the Diabetes Epidemic

Chapter Two outlined the responses to diabetes at a global scale. It illustrated the role of ideologies in shaping the institutional responses to diabetes. Several of these ideological concepts and themes have influenced New Zealand's responses to increasing diabetes rates. The national political and economic structure and restructuring of the health system has influenced the way diabetes has been addressed, for example in the nature of institutions. This section will outline the role of national ideologies and discuss the importance of the voluntary sector. This discussion will create a synthesis between global responses and diabetes in a New Zealand context.

New Zealand's response to diabetes is also illustrated through a discussion of two local initiatives for diabetes prevention and education.

4.5.1 The Influence of National Health System Restructuring

Responses to diabetes do not develop in a vacuum. They are influenced by the social, political and economic environment of a given place. It could be argued that the changes in responses to diabetes are reflected in the changes in the structure of the government and the health system (Barnett and Barnett 1997; Hornblow and Barnett 2000; Barnett and Barnett 2003). The health system in New Zealand is based on the social philosophy that access to health care should be based on need rather than ability to pay (National Economic Research Associates (NERA) 1993). This philosophy reflects the nature of the health system in the United Kingdom. However, over time the structure of health care provision has changed, influencing the role of the voluntary sector and responses to diabetes.

By the end of the 1940s a tax-funded health service was completed which was largely public in terms of hospital services, but private in terms of general practice. The New Zealand welfare state had many elements of similarity welfare system in the United Kingdom. For people with diabetes, which at this time was uncommon, there was an increased use of hospital services for diabetes care and general practitioners had a limited role in the provision of this care. People with diabetes were often referred to the hospital to receive insulin. There was also a lack of emphasis on diabetes education during this period (Beaven 2004 pers comm). Up until this time the role and importance of the voluntary sector for diabetes was not emphasised, in fact collaboration between people with diabetes was discouraged by the New Zealand Medical Association (Beaven 2004, pers comm). However, the size and extent of welfare state, in New Zealand and elsewhere, the United Kingdom and the USA, came under attack during the 1970s and 1980s as 'New Right' policies were formulated to counter the recession (Johnston et al 2002).

By the 1970s the health system in New Zealand was highly fragmented (NERA 1993; Laugesen and Salmond 1994; Dew and Davis 2005). Total health expenditure had increased but the system showed signs of strain. Subsidies that were available for primary care were constantly modified and distributed on an ad hoc basis. Therefore

primary care services were extremely difficult to access for low income groups. As a consequence the 'free' hospital out-patient facilities were increasingly utilised, lengthening waiting lists for out-patient services. Public health services were organised centrally during this time and were fragmented. There was tension and cost-shifting between central and periphery areas. Given the low prevalence of diabetes and the fragmented health sector diabetes may not have been seen as a priority by public health services. Furthermore, the dominance biomedical model and approach to health may have also influenced health care provision. Therefore preventative health care may not have been the focus (NERA 1993; Laugesen and Salmond 1994).

During the 1980s there was a shift in the rationale of the New Zealand Government and the institutional arrangements for public service administration (Gauld 2004). The 'new public management' (or 'managerialism') movement had a profound impact on public sector restructuring and on the health sector; it is deeply embedded in the neo-liberal idea of minimalist state intervention (Kearns and Joseph 2000). A hallmark of managerialism was the emphasis on economic and managerial performance ahead of any other indicators of government performance, for example a reduction in diabetes incidence (Kearns and Joseph 2000; Gauld 2004 Dew and Davis 2005). For the health sector, managerialism saw a greater authority being given to management and the introduction of market competition (Barnett et al 1998).

For public health, there have been advantages and disadvantages of managerialism. Perhaps the main advantage was the ascendancy of public health's status with the establishment of a Public Health Commission in 1992 (Davis and Dew 1999; Gauld 2004). However, despite the increased status problems arose for public health under the new system. Concerns were raised over service fragmentation, diminished information-sharing and decreased collaboration, especially with Maori and general practice, and the inefficient, costly and fragmented purchasing arrangements (Malcolm et al 1996). However, in 1995 the Public Health Commission was abolished (Malcolm et al 1996; Barnett and Malcolm 1998; Barnett and Barnett 2004; Gauld 2004). The elimination of the high status of public health with the decommissioning of the Public Health Commission questioned the National Government's commitment in this area (Barnett and Barnett 2004). It is also argued that some public health strategies were contentious and worked against the neoliberal ideals and the government's focus on the economy (Gauld 2004).

For health services in New Zealand, 'new right' imperatives led to the application of a targeted, income tested, health benefits regime which provided a competitive managed market, based on the separation of purchasers and providers. The changes, proposed in 1991 and implemented in 1993, had a major influence on health-related non-governmental organisations (NGOs) (Barnett and Barnett 2004). The reforms provided health NGOs with an opportunity to enter the 'health market'. A key feature of the restructuring was that funding was devolved to the four Regional Health Authorities (RHA's) and they were free to contract with any community, health or hospital provider that met their specifications. Therefore the community-orientated and flexible nature of many community organisations was attractive to RHA purchasers (Barnett and Barnett 2004). However, a paradox remained, despite the increased growth in the participation of NGOs in the health market many NGOs felt undervalued and unrecognised.

The introduction of competition, a feature of this reform rhetoric, is now seen to have had limited importance for ensuring equitable access for health care services (Barnett and Barnett 1997). Health services during the reform period were characterised by high charges, limited access to general practitioners and a 50% increase in waiting lists. Hospital user charges were also introduced, although withdrawn following public outrage (Hornblow and Barnett 2000). Prevention and education were not viewed as priority areas and given the often inequitable access to and the competitive nature of and health care services people with diabetes may not have received adequate diabetes. This episodic and acute care is not appropriate for people with diabetes (Melkus et al 2004). Given the high cost and limited access to general practitioners the role of the diabetes societies for diabetes educational provision may have been highly important during this time.

Hornblow and Barnett (2000) argue that the imposition of market-oriented reforms rejected established community values and was not an exercise of bold leadership, but one of political arrogance. The reforms polarised clinical and commercial cultures in the health sector. The emphasis of one culture over another brings challenges, conflicts and changes in power-structures, decision making, resource allocation, social structures and dominant values and beliefs. A fundamental lesson of these reforms is that a market-led approach has major limitations for health care delivery (Hornblow and Barnett 2000).

4.5.2 Towards a Population Focused Health Policy

A change of government during the late 1990s saw a move away from market-led initiatives. This change occurred with the New Zealand Health Strategy and the formation of 21 District Health Boards (DHBs) to replace the four RHAs. DHBs have an increased interaction with other local service providers. For example, the retinal screening program for diabetes involves a national policy initiative that is implemented regionally through the DHBs. The DHBs then contract ophthalmological services to local optometrists or diabetologist. Mobile retinal screening facilities have also been introduced in certain parts of New Zealand to increase coverage and utilisation. The new system led to a population based approach to health care and a prioritisation of diabetes within policy documents.

Diabetes was re-framed as a public health issue and incorporated as a health priority area (Barnett 2004, pers comm; MoH 2004a). A population based approach is more in line with current public health ideologies. For example, there is an emphasis on health prevention and education. All levels of society, national, regional and local are involved with decision making which leads to innovative health policies. The Primary Health Care Strategy also has a strong population focus and emphasises the empowerment of individuals and the involvement of local communities and enrolled populations (MoH 2001). The recognition of the importance of diabetes and diabetes education led to the establishment of Local/Regional Diabetes Teams (LDTs). The establishment of the LDTs is part of the new politics of the 'Third Way'. These teams attempt to incorporate all stakeholders in the provision of diabetes care and educational services and encourage collaboration and service integration. LDTs also make recommendations to the DHBs in relation to targets for diabetes and diabetes services (HFA 2000). However, the success and outcomes of LDTs and extent to which collaboration and service integration actually occurs in all areas of New Zealand is unclear. Diabetes New Zealand and the diabetes societies have an important role within the network of diabetes care and educational providers, however, there is the specificities of the their role and how it varies between places in New Zealand and the extent to which they are incorporated with the network of providers is unclear.

4.5.3 The Voluntary Sector: Diabetes New Zealand

Voluntary organisations are a significant health provider in New Zealand (McDonald 1993; Milligan 1998; Zauks 1998; Milligan 2000; Wilson 2001; Conradson 2002). The voluntary sector is a key mechanism for the delivery of cost effective care that is responsive to local needs as they are situated in community-based environments. Voluntary organisations can be seen as more flexible, in terms of service provision, than the for-profit sector. They also provide a mechanism for democratic participation and are a powerful medium for orchestrating social change, for example the allocation of health resources. However, voluntary organisations do not develop evenly and have a heterogeneous nature (Wolch 1990; Milligan 2001). Although flexible, they are still bound by the national and regional health structure, the nature of other health service providers and the culture surrounding local action. Therefore, the Diabetes Societies in New Zealand may vary in role and operation within the network of diabetes care and educational providers.

Diabetes New Zealand was developed out of a concern raised by people with diabetes over their lack of knowledge and understanding of diabetes upon diagnosis. It was assumed that the general practitioner would provide all the necessary information. However, following diagnosis very limited or no diabetes education was provided by their general practitioner. There was also a lack of state intervention and acknowledgement of diabetes. Significant gaps in diabetes-related health service provision existed during this time (Beaven 2004, pers comm). Although turned down by the Medical Association to form a society and collaborate with other people who had diabetes, due to the 'political' nature of such a request, with the support of local medical specialists⁸ and strong local leadership, from a small number of people with diabetes, a diabetes association was formed in Christchurch, New Zealand in 1955.

After much confrontation diabetes associations also developed in Auckland and Nelson and, along with the Christchurch association, held yearly meetings in Wellington (Beaven 2004, pers comm). Officially founded on 17th February 1962, and originally known as the 'Diabetic Association of New Zealand', there were 7 affiliated member societies and approximately 750 members. The diabetes association, members, and medical advisors acknowledged, when health professionals

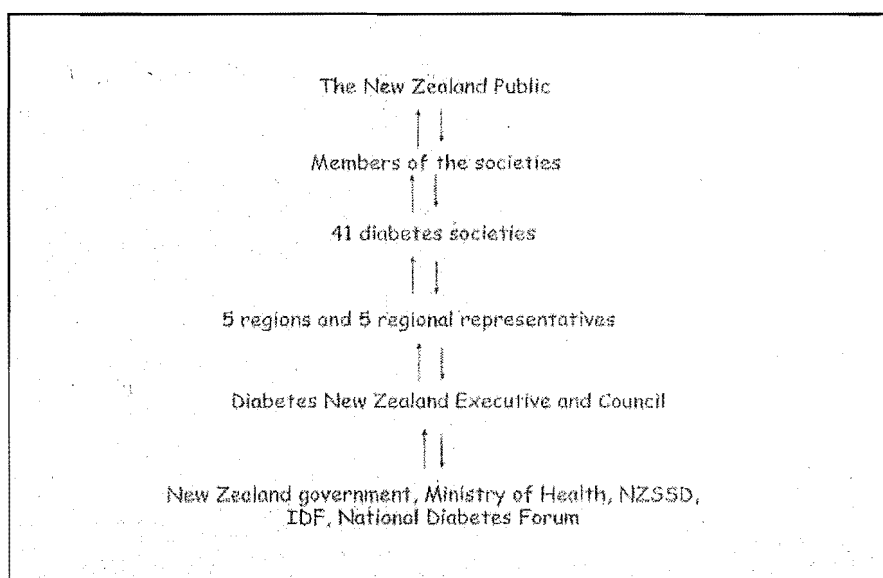
⁸ Professor Don Beaven and Dr H.R.Donald

did not, the importance of self-sufficiency, education and understanding of diabetes and the importance of these factors for people with diabetes. Despite the lack of state intervention the diabetes association gradually grew and today, known as Diabetes New Zealand Incorporated (DNZ) there are 41 affiliated societies and 13,500 members.

Diabetes New Zealand Incorporated (DNZ) is a nation wide non-government, non-profit organisation and has an important role within the network of diabetes care and educational providers. DNZ aims to provide a positive, empowering and encouraging environment for those with diabetes and their families. It is funded predominantly through membership fees, donations, grants and bequests (Dawson 2002; DNZ 2003). Unlike other voluntary organisations DNZ does not receive funding from the state. This may affect its role and operation in society. DNZ may be more flexible in its operation due to limited state regulation, however, its profile may be lower due to a lack of state funding.

At a national level, Diabetes New Zealand interacts with the Ministry of Health, the New Zealand Society for the Study of Diabetes, and the National Diabetes Forum among others (Figure 4.1). The 41 affiliated societies span from Whangarei to Invercargill.

Figure 4.1: The Structure of Diabetes New Zealand



Regional representatives liaise with the DNZ council and executive, subsequently coordinating national matters with the local societies in their specific region. This is

very much a two-way relationship, as individual societies can also use their regional representative to voice their concerns at the national level. The individual societies then work within their communities, and the network of diabetes care and educational providers, advocating on issues that affect people with diabetes.

Although a non-profit organisation, DNZ is a significant resource for the New Zealand Government, as both DNZ and the Ministry of Health promote similar health messages in relation to diabetes and general health and well-being. According to the latest Price Waterhouse Coopers *Agency Research Report* (2004), the value added to the New Zealand economy by Diabetes New Zealand is estimated to be between \$1.9 and \$3.4 million annually. Furthermore, the number of volunteer full-time equivalent jobs created by Diabetes New Zealand is 56, placing it an equivalent position to the top 5% of profit making organisations. Therefore DNZ and the affiliated societies make a valuable contribution and have an important role within the network of diabetes care and educational providers. However, DNZ and the affiliated societies are not the only diabetes service in New Zealand that provide awareness and education.

4.5.4 Examples of New Zealand Initiatives

In line with a more population focus for health and the identification by the Ministry of Health of the increased risk for Maori, Pacific Islanders and people in more deprived areas in developing diabetes two local initiatives, the South Auckland Diabetes Plan and the Te o Wai Rona Diabetes Prevention Strategy, illustrate another way in which increasing diabetes rates have been responded to in New Zealand (MoH 2002c). These locally driven initiatives aim to provide education and awareness of diabetes. They also illustrate the how public health and health promotion concepts are incorporated into health strategies and health care delivery at the local level.

Previous research also indicates that the local delivery of diabetes education in New Zealand is uneven (Simmons et al 1994a). This may be between places, socio-economic groups or ethnic groups it could also be related to gaps in the provision of educational and other diabetes services or accessibility to services. Therefore, the development of such local initiatives may also be in response to a gap in regional

health care services, in relation to service availability or cultural appropriateness of the services that are available. These initiatives also demonstrate the importance of both structure and agency for health care. For example, the health care structure and ideological framework, namely a population focus that emphasises prevention, may have provided a platform for development. Without local support, leadership and commitment such initiatives may also not have developed. The following sections will briefly outline these initiatives.

South Auckland Diabetes Plan

The South Auckland Diabetes Plan is an example of a targeted diabetes strategy aimed at reducing the incidence and increasing awareness of diabetes in South Auckland. South Auckland is a highly deprived area of New Zealand. Maori and Pacific Peoples represent 30% of the population in South Auckland and have a high prevalence of obesity, type 2 diabetes and low levels of physical activity (Simmons 1996a; Statistics New Zealand 2002a; 2002b; 2002c). In light of the high proportion of at risk groups and the potential for a rising incidence of diabetes in South Auckland it is necessary that preventative and educational strategies are implemented (Flemming et al 1995). Diabetes education is seen as a fundamental component of effective diabetes management. Therefore, the plan attempted to stimulate local efforts to meet local needs in relation to diabetes and diabetes education. The plan defined strategies at the primary, secondary and tertiary level which addressed education and prevention and encompassed the social and financial costs resulting from diabetes (Simmons et al 2000).

The recommendations engaged with issues relating patient and community empowerment and improving access to diabetes services. The specific local needs were clearly defined and specifically addressed those activities that were unlikely to be undertaken in general practice or secondary services and to help implement objectives defined within the plan (Simmons et al 2000; Simmons et al 1994). Since its inception the South Auckland Diabetes Project has put into action several mechanisms to prevent diabetes and diabetes related complications at a minimal cost to the patient. For example, South Auckland Health and North Health have helped to fund the removal of a \$6 tax on glucose tests and the building of a network of Maori and Pacific support groups for diabetes along with the introduction of local retinal

photography services. These services, among others, are culturally tailored and community oriented to foster local control of diabetes by communities in partnership with health professionals (Simmons et al 1996; Simmons et al 1996a; Wilson and Simmons 1994). As far as the literature suggests such initiatives have been well received. However, there is limited literature addressing whether the incidence of diabetes and diabetes related hospital admissions have decreased as a result of the plan, or if diabetes related knowledge has increased in South Auckland since the project has been implemented.

Te Wai o Rona

The Te Wai o Rona Diabetes Prevention Strategy is another example of a local diabetes initiative. It involves collaboration of many key stakeholders and emphasises community involvement. The strategy aims to stimulate local efforts to meet local needs in relation to diabetes and diabetes education. The Te Wai o Rona Diabetes Prevention Strategy was launched in the Waikato area, New Zealand. With the “diabetes fight begin[ing] in Waikato” those behind the project assert that it is perhaps the most significant step ever taken to halt the increase and predicted explosion of type 2 diabetes (One news 2004). The strategy is funded by the Health Research Council, the Ministry of Health, the Waikato and Lakes District Health Boards and other local health agencies. The aim is to reduce the incidence of type 2 diabetes among Maori within the Waikato Lakes region by 35%.

By increasing physical activity and enhancing nutritional habits through combined community action and personal care interventions and education. Simmons et al (1998) state that programmes based around lifestyle change, increasing awareness and empowerment of high risk communities can significantly reduce the risk factors and subsequently the incidence of type 2 diabetes.

These examples of local initiatives in New Zealand illustrate how diabetes prevention strategies are targeted towards specific places, as in the South Auckland Diabetes Plan, and specific population groups, as in the Te O Wai Rona Diabetes Prevention Strategy. They also illustrate how the concepts of community involvement, empowerment are incorporated at the local level and highlight the importance of

structure and agency, as the Te O Wai Rona Diabetes Prevention Strategy is endorsed and funded by the Ministry of Health and implemented at the local level.

4.6 Chapter Summary

This chapter has provided a contextual overview of diabetes and diabetes education in New Zealand. As shown there is substantial literature relating to the prevalence of diabetes in New Zealand and forecasts for the future. Exploring the compositional and contextual factors in relation to diabetes rates illustrates the need for the implementation of effective preventative and educational strategies. This information also reveals at risk groups and areas, which can subsequently be targeted for programmes such as the South Auckland Diabetes Project. Prevention and education are key approaches to addressing diabetes and trying to reduce the impact and incidence. This is especially so given the burden of diabetes, socially and economically, both for individuals and New Zealand society, many of which can be prevented with early intervention. Policy documents, for example the Primary Care Strategy, provide guidance for the implementation of local initiatives. Such documents are informed by overarching paradigms like the social model of health along with public health and health promotion ideologies and concepts. It is through these documents and individual and collective action that preventative strategies like Te Wai o Rona can be implemented to help reduce the burden of diabetes in New Zealand. Although not always mentioned in policy and strategical documents the role of voluntary organisations, namely DNZ and the affiliated diabetes societies must not be overlooked. In order to gain a greater understanding of the role of such organisations it is necessary to investigate consumer perceptions. The following chapter will outline the research strategies that have been used to investigate the role of and perceptions surround the diabetes societies in New Zealand and the extent to which diabetes educational services are utilised in Christchurch.

CHAPTER 5

Research Strategies

5.1 Introduction

This research has two objectives: firstly, to look at of the role of and perceptions surrounding the diabetes societies in New Zealand and the influence of geographical factors on these perceptions. Secondly it aims to conduct an in-depth exploration of the extent to which diabetes educational services are utilised in Christchurch. This research uses both quantitative and qualitative research techniques. Flowerdew and Martin (1997) argue that employing multiple methodologies to a research question provides a greater depth to the findings. The use of different research techniques gives insight into different perspectives and ways of understanding an issue. These techniques complement each other giving a rich data set. Although quantitative techniques are used, this research is predominantly informed by a qualitative research approach. This is due to the fact that although some data were analysed quantitatively they were interpreted and explained via a qualitative strategy. Qualitative research is concerned with “elucidating human environments and human experiences within a variety of conceptual frameworks” (Hay 2000, p4).

The aim of this chapter is to describe the research approach and investigative techniques that explore members’ perceptions of the diabetes societies in New Zealand and the extent to which educational services are utilised. The first section of the chapter will discuss the questionnaire, sample selection, administration, analysis and limitations. To investigate members’ perceptions and experiences with the diabetes societies a questionnaire was sent to members of six diabetes societies. The second section will discuss the deprivation data and data obtained from Pegasus Health. This data gave an understanding of the factors that influence utilisation of educational services. The third section of this chapter discusses the in-depth qualitative methodologies that were used during this research to investigate the extent to which diabetes educational services were utilised in Christchurch. The two main

qualitative techniques used were focus groups and interviews. However, it is first necessary to briefly reflect on my research experiences.

Throughout this research I have spoken to many people in relation to their diabetes and their experiences with diabetes educational services. My positionality as a white, New Zealand European and a university student resulted in an interesting experience during the focus group. I was constructed as an 'outsider' by some participants and referred to as 'you', as if I represented an entire group of people. However, being a female enabled, especially the female, participants to talk and discuss issues very openly, they felt comfortable with me as I was also a woman. I felt privileged to be a part of the focus group and interviews and respect the open and honest way in which people talked with me.

5.2 Investigating what the Diabetes Society Members Think: The Questionnaire

Diabetes society members were surveyed through a questionnaire. This questionnaire aimed to explore their perceptions and experiences of their diabetes society. This questionnaire employed both quantitative and qualitative strategies by including closed and open questions. This variation allows the generation of a holistic and comprehensive data set (Flowerdew and Martin 1997; Kitchin and Tate 2000; de Vaus 2002). In the context of this research the questionnaire is observational, as phenomena are observed rather than tested (Bowling 2002). As such conducting a questionnaire is an applicable methodology to investigate the role of the diabetes societies in New Zealand and explore member's perceptions. This section discusses how the sample was selected, the questionnaire design, piloting, the administration of questionnaires and data analysis.

5.2.1 Selecting the Six Diabetes Societies

Prior to administering the questionnaire (refer to section 5.2.4), phone interviews were conducted with the 41 society presidents. Interviews were a way to establish initial contact with the diabetes societies and build a rapport with the president of each society. The establishment of this relationship is an important part of conducting

research (Hay 2002). The interviews gave an understanding of how individual societies operated within the network of diabetes care and educational providers, along with the size and structure of each society. Interviews also helped to inform the selection of six diabetes societies for further investigation through the administration of a questionnaire.

The selection of the six societies was based on three criteria. First, whether the society was situated within a rural or urban environment, this is important as diabetes rates vary between rural and urban areas. Therefore it is necessary to investigate if perceptions of educational services also vary between rural and urban areas. Second, the model of regional health care organisation, for example whether it was centralised or decentralised. The organisational structure of the health care system has been shown to influence health outcomes (Brown 1998; Brown and Barnett 1992). For example, Brown (1998) found that hospital bed supply is related to diabetes hospitalisation. Therefore it is important to understand how the organisational structure effects people's perceptions and experiences. The third criterion is population characteristics, for example, proportion of Maori living within the area. The proportion of Maori within an area was included as Maori are considered a high risk population group in relation to developing diabetes (Ministry of Health 2002c). Six societies were chosen, based on these criteria and material generated from phone interviews.

The names of the societies and interviewees have been changed in order for their identities to remain anonymous. It was necessary to do this due to the sensitive nature of the data that emerged (Tolich and Davidson 1999). However, place-based characteristics have been used to identify the variations that emerged between, for example rural and urban based societies, but I have kept these descriptions as anonymous as possible.

Societies A and Society B are both located within large urban areas that have different models of regional health care organisation. Society A is situated in a more centralised organisational structure (Area A), and Society B is situated in a more decentralised structure (Area B). Societies C and D are smaller urban areas. Society C has a lower proportion of Maori and Society D has a higher proportion of Maori. Societies E and F are situated in rural areas of New Zealand.

The six diabetes societies that were surveyed were classed as either rural or urban. This classification enabled the variations between rural and urban society member's perceptions to be investigated. It is recognised that there are problems in defining 'rural' and that in practice rural areas vary markedly. Definitions may be based on different aspects of the socio-spatial environment, for example, statistics, agriculture, scattered pattern of service outlets, function, dispersed settlement patterns with low population totals and/or population size and density (Johnston et al 2000; Halfacree 1993; Nutley 1992). Furthermore, it is also necessary to take into consideration the perceptions residents and the extent to which they perceive themselves as rural when defining 'rural'.

For the purposes of this research two diabetes societies were defined as rural, based on their low population density, low population totals in relation to the other societies and their smaller number of diabetes related services. The other four societies were classed as urban. It is also important to recognise that even within the societies that are considered 'urban' there are several members who live on the peripheral, 'rural', areas of these cities. Although there is a difference between the number of rural and urban respondents it is felt that this is relative to the differences in population size of the 6 areas and the differences in diabetes rates between rural and urban areas, as discussed in Chapter Two.

Two of the six societies were chosen to investigate the influence of mode of health care organisation on member's perceptions of the diabetes society. The classification of Society A as centralised and Society B as decentralised was based on information obtained from an interview with a representative from Primary Health Organisation in Area A. Along with information obtained the district health board websites of the respective areas.

5.2.2 The Questionnaire Design

The questionnaire that was sent to diabetes society members addresses the first research objective: to look at of the role of and perceptions surrounding the diabetes societies in New Zealand. The second part of this objective involves an investigation of how geographical variations, urban/rural differences and different modes of organisation affect member's perceptions. This research objective involves four key

questions. First, who belongs to the diabetes societies and do any trends emerge within membership characteristics? Second, to what extent do members perceive their society as being effective in dealing with increasing rates of diabetes? Third to what extent are members involved with their society? Fourth, to what extent do members prefer the society as an educational provider? Investigating who belongs to the diabetes societies also identifies what groups are under represented. These four key questions informed the structure of statistical analysis. The questions are also readdressed in and form the basic structure the Chapter Six, which discusses the results from the questionnaire.

To gain insight into the role of the society and members perceptions, the questionnaire used open and closed questions, along with response scale questions (Appendix 1). An appropriate information sheet was attached to the questionnaire, which informed respondents about the purpose of the study and gave relevant contact details, should they require further information (Appendix 1a). It also assured respondents of confidentiality and anonymity.

The questionnaire was split into five sections. For example, four questions addressed the characteristics of members, such as, age, gender and occupation. Also given that members addresses were recorded and geocoded this enabled the construction of a socioeconomic (deprivation) profile for each society (see section 5.3).

There were four questions that addressed members' views of the effectiveness of the diabetes society. Effectiveness was measured by asking members to tick the option that they thought most appropriate for dealing with diabetes, for example, through the diabetes societies, through medical centres, by encouraging self care, through technologies and through advertising. As multiple options were chosen the options were coded separately. Members were also asked to rate the effectiveness of their society in dealing with the growing of diabetes in their area. The scale had five options, ranging from 'very effective' to 'very ineffective'. Effectiveness of the local societies was also gauged through an open question pertaining to how the diabetes society has helped people in their area with diabetes, and what the main purpose of their diabetes society is. These questions also provided insight into the role of the diabetes societies.

Several questions were asked in relation to members' level of involvement in their society. Being involved with the diabetes society relates to for example, attending meetings or assisting with the annual diabetes awareness week. Involvement differs from utilising the services of the diabetes society. Utilisation relates to receiving newsletters and magazines, and purchasing products from the society or the Diabetes New Zealand Shop based in Oamaru. Involvement was measured by using a response scale question, where members were asked to rank their level of involvement from being 'always involved' to 'never involved'. Members were also asked to indicate how much interaction they had with other people who have diabetes, to assess the importance of social support for people with diabetes.

Sections two and three of the questionnaire relate to diabetes care and education. These questions investigate members' perceptions of and where they receive their diabetes education. Questions relate to where members receive their nutritional advice, diabetes management advice and exercise advice, for example, a range of options were provided for members to choose from. Questions 16 and 17 were a response scale in a table format. These tables provide a list of providers and ask members to rank their level of preference for each provider and how much education they receive from each provider. These questions enabled member's preferences of various providers and how much diabetes education they received from each to be measured.

5.2.3 Piloting

A pilot questionnaire was conducted at the local diabetes society. Ten society members invited to take part in the pilot questionnaire. The ten members were selected randomly from the society's volunteer/members database. A discussion of the questionnaire and individual questions was then facilitated by the researcher enabling detailed feedback to be obtained. The pilot enabled the questionnaire to evolve and be developed, for wider administration, with greater clarity, conciseness and avoid ambiguous and leading questions. Piloting is a standard practice for most survey techniques. A pilot study enables the viability and efficiency of the questionnaire itself and individual questions to be assessed. By conducting a small scale simulation of data collection, issues that may cause complications at a later

stage, during questionnaire administration, can be identified and subsequently remedied (de Vaus 2002; Flowerdew and Martin 1997; Kitchin and Tate 2000).

In addition to a pilot, consultation with local health professionals was undertaken, with local diabetes specialists, diabetes educators and Maori and Pacific Island health providers and public health professionals, in relation to the questionnaire. This process allowed enabled questions to be worded with greater clarity and specificity. Given the experience these health professionals have had in dealing with people with diabetes it also led to the inclusion of questions that may have otherwise been overlooked. The clarity of the questions is vital for this research as questionnaires were postal and self-administered. In the case of postal questionnaires the clarity of questions is important to encourage a high response rate (de Vaus 2002; Bowling 1997).

5.2.4 Administration

Due to the need for privacy surrounding the dissemination of personal information the administration of this questionnaire was challenging. It was not appropriate for me to administer the questionnaires as that would breach the privacy between the diabetes society and individual members. Therefore, an agreement was arranged between myself and the six society presidents for them to administer the questionnaires on my behalf. This agreement involved the appropriate number of questionnaires being sent to each society president, and a diabetes society representative labelling and administering the postage of questionnaires to society members. A self-addressed-stamped-envelope, addressed to me at the University of Canterbury, was included to encourage a response.

In total, 707 questionnaires were sent to the six diabetes societies. The membership numbers of each society varied, therefore the number of questionnaires sent to each society also varied. Society A, has an 'active'⁹ membership of 904, approximately every fourth member on the database received a survey, equalling 200 questionnaires being sent. Society B has 500 members and approximately every 2.5 members received a questionnaire, equalling 200 surveys being sent. Society C has

⁹ An 'active' member relates to the current membership fees being paid and presence on the volunteer database.

approximately 200 members, and every second member was selected to receive a questionnaire, equalling 100 questionnaires being sent. Society presidents were also asked to check that a random selection of ages, sexes and both type 1 and type 2 diabetes were included within the sample population. Societies, D, E and F had smaller membership numbers. Therefore all members were surveyed. Society D, 78 members; Society E, 83 members; and Society F, 46 members.

A lower response rate is expected with self-administered postal questionnaires (de Vaus 2002; Bowling 1997). Of the 707 questionnaires that were sent, 335 were returned, giving an overall response rate of 47%. However, response rates varied for each society (Table 5.1).

Table 5.1: A Summary of Questionnaire Administration for Each Society

Society	Number of questionnaires sent	Number returned	Response rate %
Society A	200	113	56.5
Society B	200	89	44.5
Society C	100	46	46.0
Society D	78	33	42.3
Society E	83	24	28.9
Society F	46	15	32.6

5.2.5 Analysis

Questionnaires were all given an identification number and a code in relation to the area where the diabetes society was located. Data were coded into a Microsoft Excel spreadsheet. The initial coding of data was conducted by the Curriculum Evaluation and Management centre at University of Canterbury. Each response to the closed questions and response scale questions were assigned numbers and coded as such. Responses to open questions were recorded as text according to question number and questionnaire respondent on a separate Excel worksheet. Data from closed questions were then coded into SPSS, allowing for statistical analysis. From here more specific coding categories were formatted (Kitchen and Tate 2002; Bowling 1997). Where

respondents ticked multiple answers, each response option was coded rather than a number being assigned for all options. For example, question 2 asks respondents what treatment they have for their diabetes and lists 5 options, such as diet and/or exercise, insulin treated and tablet treated. As people often have more than one treatment, more than one answer was ticked. Therefore, each treatment option was coded separately.

Once coded, data were organised into themes and statistical analysis was undertaken (Bowling 1997). The themes directly related to the four key questions outlined above: who belongs to the diabetes societies and do any trends emerge within membership characteristics? To what extent do members perceive their society as being effective in dealing with increasing rates of diabetes? To what extent are members involved with their society? To what extent do members prefer the society as an educational provider? All data were analysed, using basic frequencies and chi-square cross tabulations (X^2), to provide an overview of the diabetes society membership, members' views of effectiveness and preferences of diabetes educational providers. The chi-square cross tabulations are discussed in more detail below.

The second part of the first research objective related to exploring the geographical variations that arose between different societies based upon urban/rural differences and different modes of organisation. To achieve this data were analysed using basic frequencies and chi-square cross tabulations. Using SPSS, frequencies were used to compare, for example, the level of involvement between rural and urban societies. For this question five response options were given. However, upon coding it was decided to recode the variables into and collapse the five categories into three (always/often involved, sometimes involved and occasionally/never involved) to give more succinct results. From here, a chi-square cross tabulation was then conducted to investigate the association between rural and urban societies and level of involvement (Appendix 2). The chi-square linear by linear association (p) was deemed to be significant if the value was 0.01 or lower (de Vaus 2002). According to de Vaus (2002) a smaller sample size should use 0.01 rather than 0.05 to ensure that the differences reflect real differences in the population. The chi-square linear by linear association value and significance level were reported in the results. This process was repeated for each question to investigate the level of association relating to rural and urban societies, and societies within different models of health care organisation.

Some questions on the questionnaire were not answered by respondents, for example, for Society A, only 80 out of 114 respondents answered question 30, pertaining to the effectiveness of the local society in dealing with diabetes. This non response may be related to members feeling that they did not know how effective their society was, and rather than indicating 'neither effective nor ineffective' a non response was chosen. For the purposes of this research the non responses and missing values were excluded from the statistical analysis.

5.2.6 Limitations of the Questionnaire

There were several limitations with the questionnaire which may have affected the quality and reliability of the data. It is acknowledged that this part of the research only surveys people with diabetes who are members of the diabetes societies in New Zealand. This sample may therefore give biased results. However, due to the privacy that surrounds the disclosure of health information, the diabetes societies and their agreement for administering the questionnaire on my behalf was a readily available option.

Only six of the 41 diabetes societies were surveyed. However, it was decided that a small number of societies would be surveyed in detail rather than surveying a larger number of societies in less detail. The administration of questionnaires through the diabetes societies may have resulted in bias. However, under the circumstances there were limited options for the administration of questionnaires. The overall response rate was under half (47%) which may influence the reliability of results.

The non response of members on specific questions may have affected the validity of some results as these missing values were excluded from analysis. Furthermore, the failure to state 'tick only one' resulted in difficulties when coding the questionnaire.

5.3 Deprivation Data and Pegasus Health Data

With agreement from society presidents member addresses were obtained for each of the six societies. Addresses were geocoded using ESRI ArcGIS9 with the 'ArcWEB New Zealand: Geocoding database'. The Geocoding database is a complete address Geocoding database for New Zealand and is extended to permit road and suburb

aliases. Geocoding allows each household address to be located within the appropriate meshblock. Only individual member's addressees were included in this geocoding process. For example, given the information sharing and communication between societies, some societies were also members of other societies, therefore diabetes societies and other businesses, such as pharmacies, were excluded. Several addresses, for example those beginning with PO Box, were unable to be matched by ArcGIS (Table 5.2).

Table 5.2: A Summary of Each Society's Geocoding Information

Society	Number geocoded*	Matched	unmatched
Society A	1122	1110	12
Society B	503	328	49
Society C	275	261	14
Society D	62	59	3
Society E	76	66	10
Society F	49	47	2

*This figure excludes those addresses of other diabetes societies or businesses who are members of the given society

Geocoding enabled deprivation profiles to be created for each society. The number of members was graphed against NZ Dep 2001 Deprivation Deciles. The New Zealand Deprivation Index provides a way to measure poverty or economic hardship (Crampton et al 2000). Areas are ranked in terms of relative deprivation. The deprivation decile of 1 indicates an area of low deprivation, and the deprivation decile of 10 indicates an area of high deprivation. Diabetes society members living in meshblocks of decile 10 therefore lived in the poorest 10% of all such areas in New Zealand. The Deprivation Index has been included in this research because it is important to understand how relative deprivation influences diabetes society membership and how this varies geographically. The deprivation profiles examine membership numbers rather than rates of diabetes within areas.

To account for variations in the absolute population between deprivation deciles diabetes society membership rates were calculated. This calculation expressed diabetes society membership as a percentage of the usually resident population, obtained from the 2001 census, by deprivation decile. Due to the diabetes society's catchment areas overlapping and because of highly dispersed patterns of membership it was extremely difficult to calculate rates for some of the six societies.

Pegasus Health is a Primary Health Organisation (PHO) in Christchurch and approximately 90% of medical centres are members of this PHO. They hold a comprehensive data set of the population of people with diabetes in Christchurch. There are approximately 12,000 people with diabetes in Christchurch, and there are 8,000 people on the Pegasus database. Data, pertaining to their population of people with diabetes, for example ethnicity, age, gender, type of diabetes, meshblock and address of general practitioner were requested. This data were requested during the early stages of data collection but were not received until six months after the request was placed. This delay resulted in only a limited analysis of the data being undertaken. Membership data were also obtained from the Christchurch Diabetes Society. The Christchurch Diabetes Society has a total membership of 1,200, which equates to one tenth of the total population of people with diabetes in Christchurch.

Correlations were then calculated between the percentage of people on the Pegasus Health database who were members of the Christchurch Diabetes Society and six social characteristics relating to socioeconomic status, ethnicity (% Asian, % Pakeha, % Maori, and % Maori and Pacific Islanders) and % persons aged over 50. These correlations were computed for the 115 Census Area Units in Christchurch. This data was included in this research because the results provided insight into the influence that the social characteristics, outlined above, have on diabetes society membership in Christchurch. These findings provided a context for the qualitative research to be conducted.

The Pegasus Health database does not contain all persons with diabetes in Christchurch since not all medical centres are members of Pegasus. Therefore the percentage of people with diabetes who members of the Christchurch Diabetes Society will be higher than a true figure since the denominator does not count all people with diabetes. There were also very few Maori and Pacific Islanders

represented in the Pegasus data. This may be because they do not attend Pegasus practices. The strength of correlations may have increased if more Maori and Pacific Islanders were represented.

5.4 Going In-depth: Focus Groups and Interviews

Focus groups and interviews are an important way to gain an insight into people's perceptions, understandings, knowledges and experiences (Hay 2000). Qualitative techniques, for example, focus groups and interviews, are increasingly used by geographers to explore the complexities that are embedded within everyday life "to gain a deeper insight into the processes shaping our social worlds" (Limb and Dwyer 2001, p1). Somers (1994) asserts that it is through our personal narratives that we come to know and understand our social worlds. She argues that it is through social narratives that identities are constructed. Therefore an exploration of such narratives and the emergent discourses can provide a rich and detailed insight into individual understandings.

A focus group involves a small group of people discussing a particular topic or issue and can be applied well to health-related research (Maillet et al 1996). Interaction between group members is a key element of conducting a focus group, as people often respond to the energy of a group environment. This interaction is a defining characteristic of focus groups and differentiates them from interview methods. Hay (2000) argues that the type of interaction in focus groups can lead to a lot more information being generated than in other research methods. Limb and Dwyer (2001) also assert that focus groups place people in a situation more like a social setting which allows the conversation to flow freely.

During interviews, on the other hand, interaction occurs between the interviewer and the interviewee. Interviews are valuable to gain insight into different opinions. In this research semi-structured interviews were used. This form of interviewing involves some degree of predetermined order but still allows for flexibility in the way issues are addressed by the informant (Hay 2000). Interviews can contain primary and secondary questions and both types of questions were useful for this research. Primary questions are opening questions and can be used to initiate a discussion. For

example, “who do you think are the key providers of diabetes care and education in Christchurch”? Secondary questions are those which encourage the interviewee to expand and follow up on the issue being discussed. For example, in relation to the primary question above, “have you heard of the diabetes society, and/or do you know what their role is”? Hay states (2000, p80) that interviews “bring people ‘into’ the research process”, and capture people’s behaviours, experiences and views on life and are an important way to understand lived experiences.

In the context of this research qualitative techniques are valuable. Through the analysis of the questionnaire data, the Pegasus Health data and the Christchurch Diabetes Society data a gap emerged in relation to who utilised diabetes educational services, the diabetes society, in Christchurch. Therefore, the second aim and the qualitative part of this research, is to investigate the extent to which people utilise diabetes educational services in Christchurch. Such an investigation may enable diabetes educational services to be improved. The following section will discuss the focus group and interviews that were conducted, how participants were recruited and how data was analysed.

5.4.1 Meet the Participants: Recruitment and the Research Experience

Focus Group

It was decided to conduct a focus group at the Pacific Island Health Centre in Christchurch. A contact had previously been established with an employee of the Pacific Island Health Centre, creating a rapport which aided the research process. It is recognised that the term ‘Pacific’ blurs the very real differences and diversity that are encompassed within the term ‘Pacific People’. The term ‘Pacific People’ is a contextual and contestable term and is by no means describing a homogenous group (Dew and Davis 2005). For the purposes of this research the term ‘Pacific People’ includes people primarily from countries in the South Pacific.

The Pacific Island Health Centre runs a Diabetes Support Trust, the Pacific Island Diabetes Support Trust. The Diabetes Support Trust is a group that provides support to Pacific Islanders with diabetes and their families. It is a forum to share information

and discuss ideas. Through the established contact, it was arranged to conduct the focus group at the end of a Diabetes Support Trust meeting.

Before beginning the focus group discussion I introduced myself and the research verbally. Participants were also given the opportunity to ask any questions they had before beginning. The focus group was tape recorded and subsequently transcribed allowing for close attention to be given to focus group material. I discussed with participants if they consented to the focus group being recorded before beginning and outlined the purpose of this recording. Initially five participants were present, however, one left due to a prior commitment. All participants were given an information sheet containing, information about the research and how to contact me should they require further information (Appendix 3).

The focus group was semi-structured in that I facilitated a discussion between participants by asking key primary questions (Appendix 3a). For example, who do you get most of your diabetes education from and how do you feel about this education? Have you ever been to the diabetes society? Other questions were also asked in specific relation to points raised during the focus group.

Joanne¹⁰, the employee at the Pacific Island Health Centre was present during the focus group and participated in the discussion. Joanne provided a sense of familiarity and support for participants throughout the focus group. She also helped to facilitate the discussion and translate questions when needed. It was necessary for Joanne to be present given that I am not a Pacific Islander and have had limited contact with Pacific Island culture. For this reason a focus group was chosen rather than interviews, so that participants would feel more comfortable and obtain ideas from each other for discussion.

Interviews

In-depth interviews were conducted through a medical centre in a more deprived area of Christchurch. According to the NZ Deprivation Index the chosen area is a decile 8, indicating relatively high deprivation. A contact was made, through Pegasus Health, with a practice nurse at the medical centre. A letter was sent, on my behalf, by the

¹⁰ Joanne is a pseudonym, and will be used throughout the presentation of findings in Chapter 7.

practice nurse to a random selection of 15 patients requesting their participation in an interview (Appendix 4). It was then left to the patient to contact me, and arrange a suitable time for an interview.

Three interviews were conducted. Although a small number, the aim of this qualitative fieldwork is not to gain a representative sample. Rather, it was to explore in detail people's experiences and perceptions of diabetes education in Christchurch, and to add another dimension to issues raised during the questionnaire data analysis.

Interviews were semi-structured and contained a range of primary and secondary questions (Appendix 5). As participants made initial contact with me and had information regarding the research in writing, via the letter that was sent, it was taken that they consented to the interview. I also introduced myself and the research briefly before beginning. Participants were also consulted before the interview began for their willingness to participate and their consent regarding the tape recording of the dialogue. All material was transcribed soon after the completion of each interview.

All participants, from the focus group and interviews, were given the option to view a copy of the transcript and if they would like the tape to be returned to them. However, no participants requested this. All participants have participated in interviews and focus groups have been given pseudonyms for the purposes of including transcript material in this thesis to keep their identities anonymous.

Data Analysis

A discourse analysis views data as a medium rather than something we collect (Allured 1998). Limb and Dwyer (2000) argue that it is through discourse that knowledges, understandings and identities are constructed and re-negotiated. It is necessary to explore the discourses and narratives that emerge through the data that was generated during this research. This type of research does not attempt to make claims to universal 'truths' and theories; it is situated within a local environment and aims to explore this. I do not attempt to make any general claims about Pacific Islanders or people in more deprived areas or of Christchurch, the task is to explore the specificities within which the research question is situated.

Initially, the data was read through and organised into themes to gain familiarity with the material. From here a discourse analysis was conducted. Upon analysing and interpreting the results many themes emerged. However, there were four themes that that recurred throughout data analysis and that I thought were important. The recurrence of these themes led to their inclusion in this thesis, they also formed the basic structure of Chapter Seven.

5.5 Research Challenges

A challenge throughout this research was to identify those who do not receive diabetes education and people who are considered 'hard to 'reach. Although the participants who took part in the qualitative research were not members of the diabetes society, they still received diabetes education from general practitioners and practices nurses at their medical centre and through the Pacific Island Health Centre. Attempts were made to contact people through a local community centre. However, after several phone calls and visits this process did not eventuate and given time constraints I was unable to peruse option this further. It remained a challenge throughout this research to contact people who received little or no diabetes education. This is an area that needs further attention.

In the following two chapters I will present the findings from this fieldwork and re-address the thesis aims. The findings from the questionnaire, deprivation profiles and Pegasus data will be presented in Chapter Six and the discourses that emerged from the focus group and interviews will be addressed in Chapter Seven.

CHAPTER 6

The Diabetes Societies: What do the Members Think?

6.1 Introduction

This chapter will address the first research objective of this thesis: to investigate the role of and perceptions surrounding the diabetes societies in New Zealand and the influence of geographical factors on these perceptions. The 41 diabetes societies across New Zealand have an integral role in the delivery of diabetes care and education. To gain a deeper understanding of how education is consumed within such educational spaces it is important to explore members' perceptions of the diabetes societies and the education they provide. By understanding members' perceptions of the societies it is thought that educational services can be improved to achieve better health outcomes.

This chapter has three aims: first, to investigate the characteristics of who belongs to the diabetes societies, that is, age, gender, type of diabetes and the deprivation profile of the six societies. Examining who belongs to the societies also provides insight into whom and/or which population groups do not belong and may be excluded from diabetes society membership. The second aim involves an examination of members' perceptions from six diabetes societies in New Zealand. Members' perceptions of the effectiveness of their local society, their level of involvement with the society and preferences in relation to educational providers are analysed in order to gain a greater understanding of the role of the diabetes societies in New Zealand. Third, to investigate the geographical variations that arises between different societies in relation to urban/rural differences, and different modes of health care organisation. It has been shown in the previous chapters that diabetes rates differ between rural and urban areas. Local responses are also shaped by the nature of national ideologies and institutions. Therefore it is important to examine whether members' perceptions of the diabetes societies vary between rural and urban areas, and between different models of regional health care organisation.

6.2 Overview of the Diabetes Societies in New Zealand

The questionnaires that were sent to the six diabetes societies examined members' perceptions of and the role that the diabetes societies play. The questionnaire addressed four key questions: first, who belongs to the diabetes societies and do any trends emerge within membership characteristics? Second, to what extent do members perceive their society as being effective in dealing with increasing rates of diabetes? Third, to what extent are members involved with their society? Fourth, to what extent do members prefer the society as an educational provider

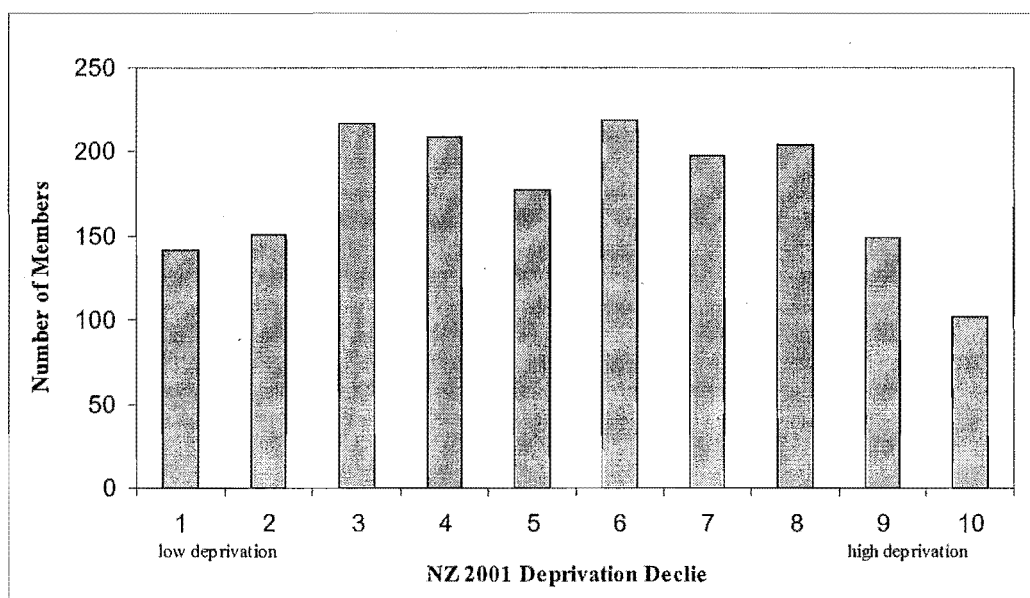
6.2.1 Who Belongs to The Diabetes Societies?

The majority of people who belong to the six diabetes societies have type 2 diabetes (69.0%). A further 24.5% of members have type 1 diabetes and the other 6.6% of members did not know what type of diabetes they had. The relatively high proportion of members who could not identify which type of diabetes they have may reflect the nature of communication between health providers and people, or the ambiguity that surrounds the definition and classification of type 1 and type 2 diabetes, as discussed in Chapter One. Furthermore, the high proportion of members with type 2 diabetes reflects that 90% of people with diagnosed diabetes have type 2 and 10% of people with diagnosed diabetes have type 1 (MoH 2002c).

The most commonly represented groups in the six diabetes societies were New Zealand European (95.3%), female (57.5%), over 60 years of age (76.4%) and retired (61.5%). This was also reported in an interview with the president of a diabetes society, it was stated that: "I'm 52 and the youngest [member]". Maori were under-represented in the six diabetes society's membership, making up 2.8% of the total. The remaining 1.9% of the society membership was classified as 'other' and comprised Pacific Islanders, Asian and other European. 9.1% of membership were people aged between 18 and 50. The remaining membership was comprised of people who were over the age of 50. The predominance of the older age group may reflect the higher incidence of type 2 diabetes among this group. Diabetes Youth Societies cater for people who have diabetes and are under the age of 18 (DNZ 2003).

There are not only age, diabetes type and gender dimensions to the diabetes society membership, but also important differences in the deprivation profiles between each society. The number of members in each deprivation category was calculated using the 2001 NZ Deprivation Index (Figure 6.1). There were fewer members in the extreme decile groups (1 and 2; 9 and 10), and higher membership levels in the middle deciles. Overall, there were 142 members in decile 1, and 102 members in

Figure 6.1: The Membership of the Six Diabetes Societies According to Deprivation Decile



decile 10. Decile 6 had the highest membership level with 219 members. This graph may reflect that within these six areas there are more areas within the middle deciles, therefore higher membership in these deciles would be expected. However, an important question can be raised, why are membership numbers lower in the higher deprivation deciles?

6.2.2 Members' Perceptions of the Society and Its Effectiveness

This section provides insight into the extent to which members of the six diabetes societies perceived their society to be an effective way of addressing the increase of diabetes. This was measured by asking respondents questions relating to how effective they thought their local society was what they thought the best way to address increasing diabetes rates and how has the diabetes society helps people in

their area with diabetes and how it helps them personally. Questions were both open and closed.

Over one third of members (36.7%) perceived the society to be very effective in dealing with the increasing rates of diabetes in their local area. A further 44.0% of members perceived the society to be somewhat effective in dealing with increasing rates of diabetes. The remaining 19.3% of members had no views on the effectiveness of their society. Some respondents indicated that they did not feel they could answer this question due to their lack of involvement with the society. Members' perceptions of effectiveness may be related to how they feel about the services their society provides, the nature of other diabetes care and educational providers in their area or levels of involvement with the society. Perceptions of effectiveness may also be related to members' views on the severity of their own diabetes. The nature of services may also vary between areas, influencing the utilisation of the diabetes society. These variations will be addressed further in the following section.

Members indicated that medical centres, general practitioners (GPs), practice nurses and primary health organisations (PHOs) would be the best/most effective way of addressing growing diabetes rates (49.0%). This was closely followed by encouraging self-care and self-monitoring (46.6%). Advertising was also identified by 40.6% of members as an effective way of addressing the growth of diabetes. Members perceived that more individually based methods, for example general practitioners, would be more effective in dealing with increasing diabetes rates. However, 33.4% of members considered the diabetes society to be the best way of addressing increasing rates. Perceptions of effectiveness may influence members' level of involvement with the society.

6.2.3 Level of Involvement in the Society

Involvement with the diabetes society means attending meetings or assisting with the annual diabetes awareness week. Over half (55.3%) of the members from the six societies indicated that they were never involved with their local society. The levels

of involvement for the remaining members ranged from being always involved (13.9%), sometimes involved (7.6%) and occasionally involved (23.2%).

In relation to who attends meetings it was suggested by several diabetes society presidents that more females attend meetings than males. For example, it was observed by one society president (President of an urban society) that “ahh mostly women, mostly middle aged, um you don’t get any of the young people [attending meetings]”. This trend also reflects the questionnaire findings, as the members of the six diabetes societies were predominantly in the older age group. The president of a rural society also commented that “access [for] males [is] very difficult...[especially] a lot of the Maori males... however I don’t know why”. Another president asserted that young men with type 1 do not come at all (President of a small rural society). These comments bring to the fore an important gender and cultural dimension in relation to accessing care. However, there was no significant association between gender and level of involvement in the diabetes society ($X^2 = 0.965$; $p = >0.05$). There was also no significant association found between level of involvement and age. The issues of gender and culture in health will be addressed further in the next chapter.

Over half of the members (59%) indicated that they utilised the services of their local diabetes society. Utilising the services of their society relates to accessing the diabetes supply scheme based in Oamaru, purchasing items or receiving magazines and newsletters, rather than direct involvement with the society. Of those members that used the society, over half suggested that they used the society to some extent: weekly (2.7%), every month (24.5%) or every three months (29.3%). The other half of the members who indicated utilising the society’s services did so every six months (21.1%) and every year (22.4%).

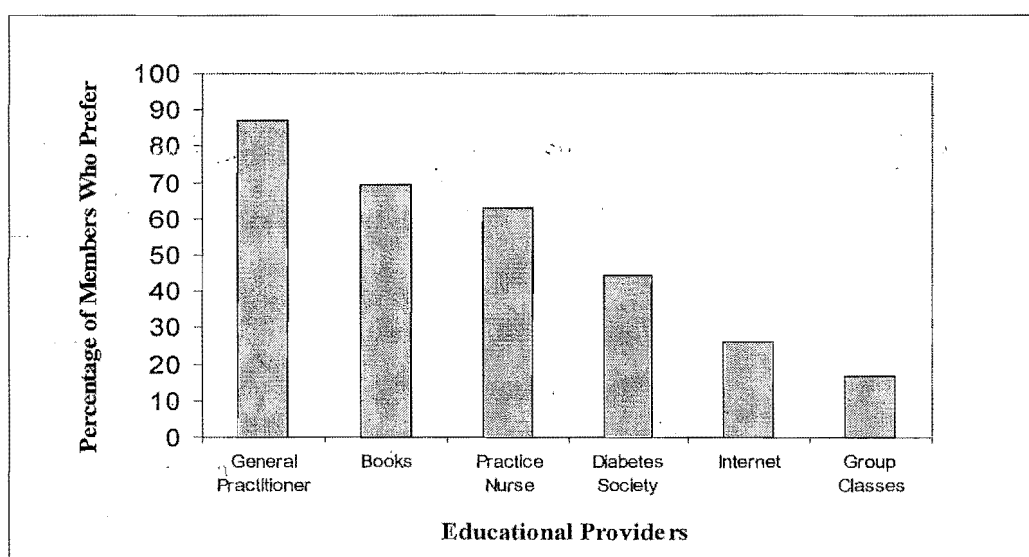
Many factors may influence members’ level of involvement within the society, for example, time constraints, other commitments or mobility. However, the fact that, 59% of members utilised their society to some extent indicates that these six societies have an important role within the network of diabetes care and educational providers in their area. The specificities of this role will be explored in more depth in a following section.

Social support for people with diabetes and creating awareness of diabetes among the community are important elements relating to diabetes care and education. The diabetes societies have an important role in the process of creating awareness and providing support. This importance is illustrated by the 34.2% of members who meet regularly with other people who have diabetes. Of those who met regularly, 62.8% shared information relating to diabetes and diabetes education. Furthermore, 50% of members expressed that their own membership to their diabetes society had enabled them to help others with their diabetes. For example, 51.3% of members talked to family and friends about diabetes and how it can be prevented. These results illustrate that the diabetes societies have an important role in social outreach among the community, which may serve to increase awareness of diabetes.

6.2.4 Diabetes Education: Preferences and Provision

As an educational provider the diabetes societies have an important role to play. However, the diabetes societies were not the preferred educational provider by most members. Figure 6.2¹¹ illustrates the level of preference for various educational providers by members of the diabetes societies. This graph illustrates that the most

Figure 6.2: Percentage of Members Who Strongly Prefer Various Educational Providers

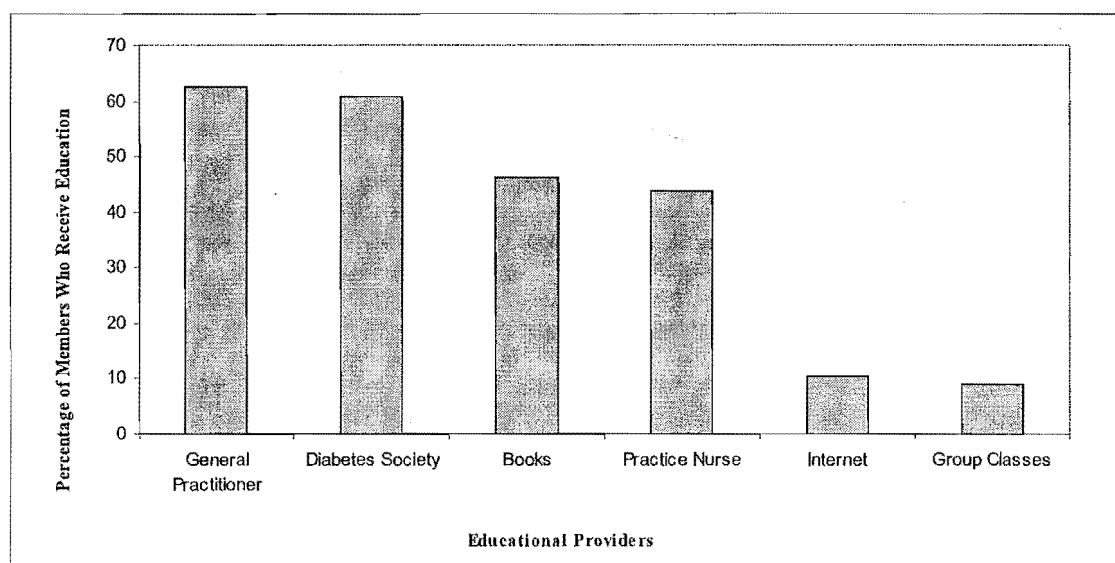


¹¹ Respondents were asked to indicate the level of preference (ranging from strongly prefer to never prefer) for each provider. Figure 6.2 illustrates the percentage of members who “strongly preferred” each provider. As respondents indicated a strong preference for more than one provider each provider was looked at separately as a percentage of those who strongly preferred each separate provider, the missing values were excluded. Therefore the total across all providers does not equal to 100%.

strongly preferred educational provider is the GP. Books were also highly preferred methods of education by well over half of the members. The results indicate that diabetes society members tend to prefer educational providers that are more individually based. The importance of the GP as a key provider, preferred by members, for diabetes care and education is also illustrated through these results.

Differences arose when comparing levels of preference with levels of actual provision. Figure 6.3¹² demonstrates the level of provision of various providers for society members. This graph illustrates that GPs were the most significant

Figure 6.3: Member's Perceptions of Level of Provision of Various Educational Providers



educational provider for members of the diabetes societies. GPs were also the preferred provider by society members. Therefore GPs continue to have a vital role in providing diabetes care and education.

It is demonstrated in Figure 6.3 that the next most significant educational provider is the diabetes society. With 60.9% of members indicating that almost all or quite a lot of their education was provided by the society. This is in contrast to only 44.6% of

¹² Respondents were asked to indicate the level of actual provision (ranging from almost all to none) for each provider. Figure 6.3 illustrates the percentage of members who received "almost all" of their education from the various providers indicated. As respondents indicated their education was provided by more than one provider each provider was looked at separately, as a percentage of those who received education from each provider. The missing values were excluded. Therefore the total across all providers does not equal to 100%.

members strongly preferring this type of education (Figure 6.2). One explanation for this is that the society may, in a sense, fill a gap between other providers. This may be because there are barriers to utilising other providers or that the society may be more available for extra advice. One respondent asserted that their society “provide[ed] info for those who don’t get sufficient advice from GP” (large urban society questionnaire respondent number 158). The importance of the diabetes societies as an educational provider for members is illustrated through these results. However, it is important to recognise that the diabetes societies only represent a proportion of people with diabetes (The Diabetes Society in Christchurch represents 10% of people with diabetes).

Figures 6.2 and 6.3 also demonstrate that more society members prefer their general practitioner as their educational provider than actually receive education from their general practitioner. A significant association was found between preference and level of provision ($X^2 = 60.433$; $p = <0.001$). These differences illustrate an interesting dynamic in terms of the nature of service provision for diabetes care and education in New Zealand. The fact that more society members prefer their general practitioner as a provider than actually receive education from their general practitioner may reflect that barriers exist for members when accessing other health providers. It may also reflect that there are fewer diabetes care and educational providers in some areas of New Zealand, and that in these areas the diabetes societies, may fill a gap. One society president commented in relation to this that “[there are] people out there who need help who can’t get to the doctor” (President of a small urban society). It is here that the diabetes societies may have a vital role to play.

The comments from the open ended questions were also a way to obtain members perceptions of the role of the diabetes societies. Members were asked to outline what they thought the main purpose of their diabetes society was, the main ways they thought the diabetes society helped other people in their area with diabetes and how the society helped them personally. According to members the societies had a variety of different roles and meant different things to different people, for example:

...by being able to greet new members and make them [the new members] feel they’re not on their own (small urban society questionnaire respondent number 08).

...emotional support (large urban society questionnaire respondent number 33)

...sit and chat over a cup of tea (large urban society questionnaire respondent number 33),

...by talking about the small problems (small urban society questionnaire respondent number 22)

...we're a circle of friends (small rural society questionnaire respondent number 06).

Members perceived the primary role of the society to share information, create awareness and encourage and give support to new members. The societies, therefore, have a vital role and offer services that may not be provided in a more clinical environment. As one member described “we’re a more friendly face”, compared with other health providers (small urban society questionnaire respondent number 32). 94.2% of members from the six diabetes societies indicated that diabetes education has helped them to implement changes in their lives to better manage their diabetes. This illustrates the importance of diabetes education and the role of diabetes society as an educational provider.

Members obtained diabetes-related information from various sources. It was found that the most commonly utilised sources were more individually based, for example general practitioners. 52.8% of members indicated that they “nearly always” received information from their GP. Pamphlets, books, brochures and other written material were “nearly always” utilised as a source of information by 52.5% of members. The diabetes societies were also significant providers of information, as 25.6% of members indicated that information was “nearly always” obtained from their society. Talking to family and friends was also a valuable source of information (16.3%).

It was found that GPs were also the principal providers of diabetes management advice for members of the six societies; 44.5% of members indicated their GP provided diabetes management advice, 22.4% indicated that their GP provided exercise advice and 25.7% relied on their GP for providing diabetes support. Diabetes

support may relate to discussing ideas about diet or sharing information about diabetes management. However, the diabetes society is also a significant provider. For example, 23.6% of members stated that the diabetes society was important for nutritional advice while a further 22.7% saw their society as being an important source of diabetes support. The society is also important for diabetes management and exercise advice, with 20.6% and 11.2%, respectively, of members indicating their society's importance for these aspects of their diabetes care and education. Although the diabetes societies are a significant provider of diabetes support, the utilisation of the general practitioner, by members, for support may reflect variations in the organisation of the diabetes societies across New Zealand.

6.3 Variations Between Rural and Urban Societies

Health services in rural New Zealand are a highly politicised issue (Burton 1999; Creech 1999; London 2002). It is also known that the incidence of diabetes rates varies between rural and urban areas, as discussed in Chapter Two. Therefore it is important to investigate the differences between rural and urban based diabetes societies. This section relates to the second aim of this chapter, in that it investigates the variations that arise between rural and urban society members. It will examine differences in rural and urban diabetes society members' perceptions of the effectiveness of the society, variations in the level of involvement between rural and urban society members and to what extent members of rural and urban societies prefer their society as a provider. It is acknowledged that defining 'rural' is problematic, for example some 'urban' societies may contain members who live in more 'rural' areas. Chapter Five outlined in more detail how 'rural' and 'urban' societies were classified.

6.3.1 Deprivation Profiles: Urban and Rural Societies

There were marked differences in the deprivation profiles between urban and rural diabetes societies, and between the overall society (Figure 6.1) and the rural diabetes society profiles. Before calculating the deprivation profiles for rural and urban societies it was expected that membership levels would be highest among a more 'middle class' socio-economic status, in the middle of the NZ 2001 deprivation index. Wolch (1990) has identified that there is a strong association with participation in

voluntary organisations and the 'middle class', with organisational profiles having a strong tendency towards this social group. In the context of this research this trend is important as there may be barriers to utilisation for highly deprived people and the presence of a stigma may be experienced differently in different socioeconomic groups. The effects of a stigma for diabetes will be addressed in the next chapter.

The findings from this research reflect Wolch's assertion. However, an unexpected trend emerged in the deprivation profile of the rural based diabetes societies. For rural societies membership increases from deprivation decile 1 to decile 10 (Figure 6.4). This suggests that membership is highest in the more deprived rural areas. The rural society profile also differs markedly from the overall diabetes society profile, which sees membership numbers being highest in the middle deciles and lowest in the extreme deciles (Figure 6.1). In contrast, the urban society profile (Figure 6.5) is consistent with the overall diabetes society profile, and reflects Wolch's (1990) assertion that volunteer organisations are predominantly 'middle class'. The urban society profile has higher membership levels in deciles 3 to 6. For the deciles 6 to 10 membership levels decreased. There were also lower membership levels observed in deciles 1 and 2.

Figure 6.4: The Number of Rural Society Members According to Deprivation Decile

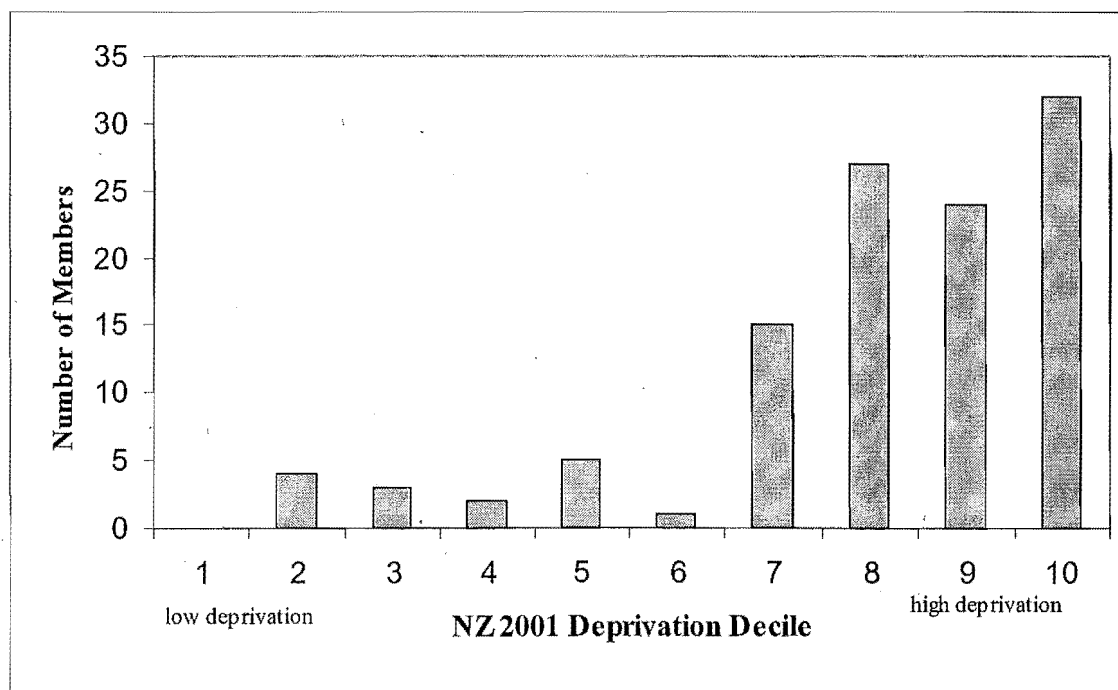
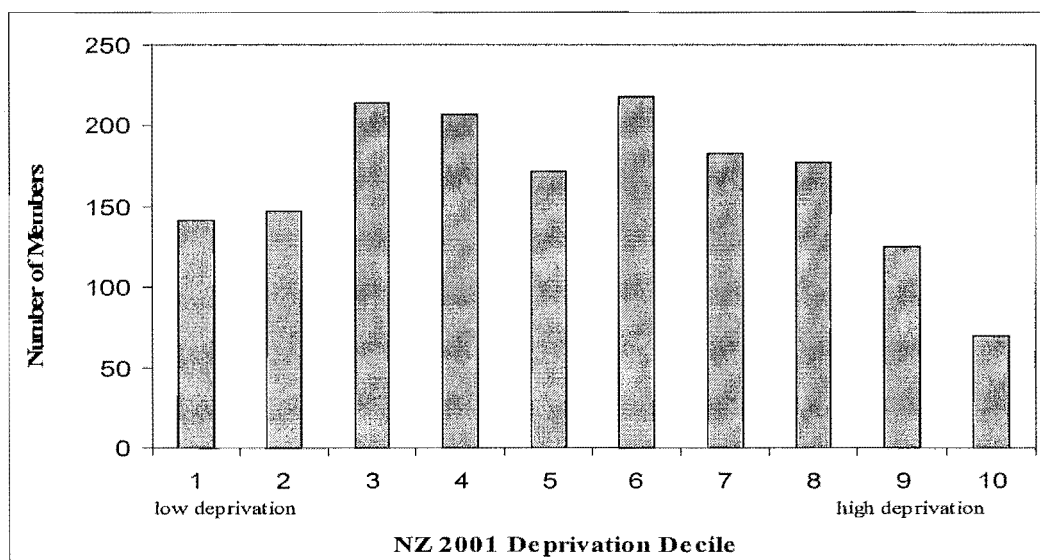
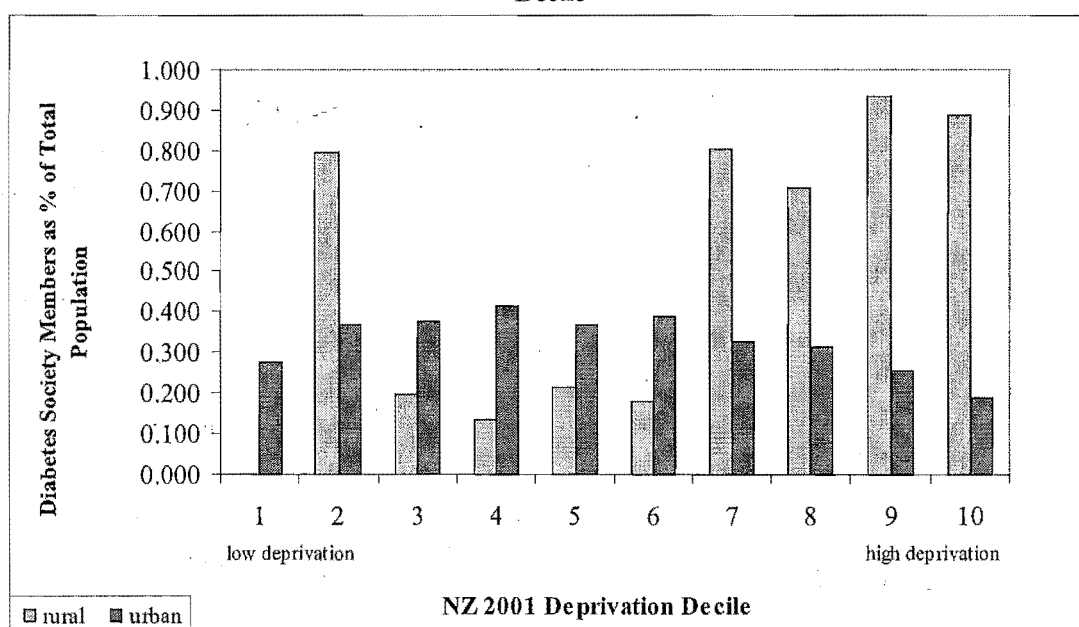


Figure 6.5: The Number of Urban Society Members According to Deprivation Decile



In order to account for variations in absolute population between the deprivation deciles the society membership rates were calculated. The diabetes society membership a percentage of the usually resident population, for the 2001 census, by deprivation decile was calculated (Figure 6.6).¹³ It was found that for rural areas there was greater participation with the diabetes society in the higher deprivation deciles (7 to 10) compared to urban societies. For urban areas, participation was highest in the middle deciles.

Figure 6.6: Rural and Urban Society Members as A % of The Total Population by NZ Deprivation Decile



¹³ However, these 'rates' need to be taken at face value due to the difficulty of determining an accurate population denominator, as local people did not always utilise their local society and sometimes went elsewhere for diabetes care and education.

The differences between the deprivation profiles and membership rates for rural and urban societies may reflect the nature of individual societies in rural and urban areas. For example, it may suggest that the smaller scale of rural diabetes societies encourages more interaction and, in turn, influences levels of participation. It may also reflect that in rural areas if other diabetes care and educational providers were less available the diabetes society may be increasingly utilised, encouraging greater rates of participation. The greater number of highly deprived people who are members of the rural diabetes society may suggest that rural diabetes societies are more effective at reaching hard to reach groups, namely more deprived people, than urban societies. Therefore, these results illustrate that socioeconomic status affects utilisation of and access to diabetes educational services (Dahlgren and Whitehead 1992; Gatrell 2002; Agardh et al 2004; Marmot 2004).

Figures 6.4, 6.5 and 6.6 may reflect the socio-economic characteristics of these places rather than the characteristics of diabetes society members. For example, there may be more deprived areas in rural New Zealand. Therefore a greater number of members from higher deciles would be expected. However, it could be argued that even in deprived areas the more affluent would still be more likely to join the diabetes societies.

6.3.2 Members Perceptions of Effectiveness

There were differences between rural and urban society members' perceptions of the effectiveness of their diabetes society. For example, 57.8% percent of members from rural societies perceived their society to be very effective in dealing with diabetes in their area, compared with only 32.0% of urban society members. Chi-square analysis also revealed a significant association between rural and urban societies and members' perceptions of effectiveness ($X^2 = 9.691$; $p = <0.01$).

Members were asked to consider what they thought was the best way of dealing with the growth of diabetes at a national level for example, through the diabetes societies, through medical centres (GPs and practice nurses) or through encouraging self-care or through advertising. Rural society members perceived the diabetes societies to be one of the most effective ways of managing increasing diabetes rates (50%). In

comparison, only 30.5% of urban society members perceived their diabetes society as being an effective way of managing increasing diabetes rates. A significant association was also found between rural and urban societies and the diabetes society as 'the best way' to deal with increasing diabetes rates ($X^2 = 7.226$; $p = <0.01$). Members of rural and urban societies considered encouraging self-care (48.0% and 46.3% respectively), medical centres (47.9% and 49.5% respectively) and advertising (42.0% and 40.4% respectively) similarly as being important ways to address increasing diabetes rates.

These themes were also reflected in comments made by diabetes society presidents. For example, the president of a small rural society said that "country places do more than big city ones" and another rural society president commented that the "city's different, in terms of access". These ideas create a distinction between the 'city' and the 'country' and serve to construct the 'city' as a distinctive other for people in more rural areas. The differences between rural and urban societies may be related to the different nature and structure of rural and urban based diabetes societies. Rural and urban societies may operate differently within the network of diabetes care and educational providers due to differences in the availability of other health providers between rural and urban areas. For example, rural societies may take on a different role and reflecting different needs within the local community, for example in rural areas, the diabetes society's responses may reflect the lack of availability of GPs or other diabetes specialists (The Royal New Zealand College of General Practitioners 2002).

6.3.3 Involvement in the Society

Members of rural societies were more involved with their society compared to urban society members. For example, 24.4% of rural society members were always involved with their society, compared with only 12.1% of urban society members. Rural society members had a statistically significant level of involvement with their society compared with members of more urban societies ($X^2 = 17.730$; $p = <0.001$). Members of rural societies also met more regularly with other people who had diabetes than urban society members (50.0% and 31.6% respectively). These results may indicate that the smaller size of rural societies encourages greater levels of

involvement. People with diabetes may also be more aware of the diabetes society and their role due to the smaller size of rural communities and a greater level of community interaction from society members, which also helps to create awareness.

Members of rural societies were more likely to help others with diabetes due to their own membership of the diabetes society compared with urban society members (60.0% and 48.0% respectively). However, no significant association was found. A greater percentage of rural society members (63.0%) compared to urban society members (48.8%) spoke to family and friends about diabetes and diabetes can be prevented. The role and importance of social support can be identified through these results, as well as illustrating the importance of social outreach. Meeting with other people and sharing information also creates awareness of diabetes among the community. Therefore, the diabetes societies have an important role in providing social support and fostering community outreach and awareness.

Differences between rural and urban societies also emerged in relation to levels of satisfaction with support from family and friends. Members of rural societies were more likely to be 'very satisfied' with their level of support from family and friends than members of the urban societies (51.1% and 37.7%) ($X^2 = 10.061$; $p = 0.001$). These findings indicate that the greater level of communication and interaction between rural society members may result in greater feelings of satisfaction in relation to support.

6.3.4 Preferences and Providers

Marked variations arose between and within rural and urban societies in relation to diabetes care and educational preferences (Table 6.1). Variations also arose between rural and urban society members in terms of who provides their diabetes care and education. These results illustrate that GPs and practice nurses are the preferred provider by members of rural and urban societies. It is also evident that rural society members strongly prefer their diabetes society, as an educational provider, to a greater extent than those urban society members. This finding illustrates a preference towards more individually based providers.

Table 6.1: Level of Preference and Actual Provision of Various Educational Providers for Rural and Urban Society Members

Educational provider	Rural societies %		Urban societies %	
	Strongly/usually prefer	Always provides	Strongly/usually prefer	Always provides
Doctor/GP	97.2	74.2	85.4	60.8
Practice nurse	82.4	58.6	59.2	41.5
Diabetes society	66.7	85.2	40.8	57.4
Internet	12.5	13.3	28.3	9.9

In more rural areas, the diabetes societies are significant providers, with 85.2% of rural members indicating that almost all of their education was provided by their diabetes society. This is in comparison to only 57.4% of urban society members, illustrating that there may be a lack of availability of other diabetes educational providers in rural areas. The importance of the diabetes societies, as an educational provider, is illustrated by the 97.9% of rural and 93.5% of urban society members who believe that diabetes education has helped them to implement changes in their lives enabling better diabetes management.

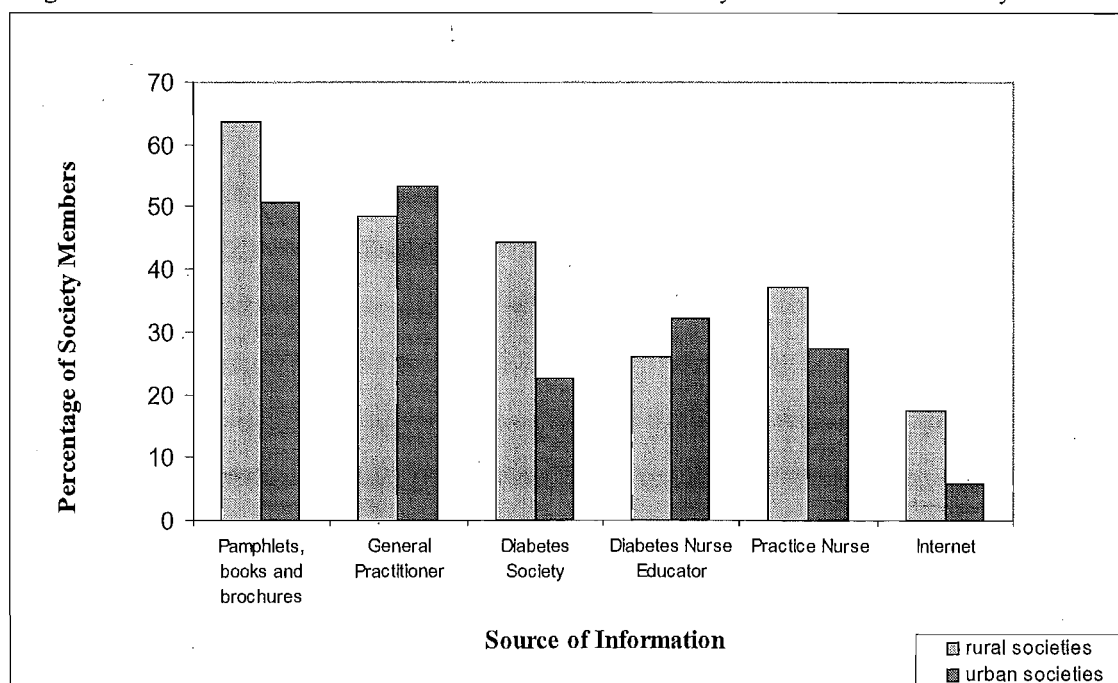
The diabetes society was found to be a significant provider of diabetes education for members; 97.2% of rural society members preferred to receive their diabetes education from their GP while only 74.2% of members did so (Table 6.1). However, only 66.7% of rural society members preferred the diabetes society as an educational provider, while 85.2% of members received almost all of their diabetes education from this provider. Similar results were observed for urban societies (Table 6.1). A significant association between provider preference and actual provider for both rural ($X^2 = 9.877$; $p = < 0.01$) and urban ($X^2 = 50.673$; $p = < 0.001$) societies was found. These results may indicate that, although GPs were the preferred provider, barriers to utilising GPs may exist. Barriers may be in relation to cost, availability or satisfaction. It could be argued from these results that the diabetes societies fill a gap for members in relation to other diabetes educational provision.

Over half of the members from both rural and urban based societies saw their general practitioner in the first instance for their diabetes care (56.0% and 69.8% respectively). A significant association was also found ($X^2 = 3.710$; $p = 0.05$). The utilisation of the general practitioner illustrates the important role of the GP as a first point of call for diabetes care and education (The Royal New Zealand College of General Practitioners 2002). The difference between rural and urban society members in seeing their GP in the first instance may suggest that there are differences in the availability of doctors between places or that certain barriers exist in terms of accessing care.

It was found that for rural society members, the diabetes society was the most commonly utilised provider, compared with GPs for urban society members. A significant association was also found between rural and urban societies and the utilisation of the diabetes society ($X^2 = 18.807$; $p = < 0.01$). This contrast may reflect the nature and availability of providers in more rural areas. For example, perhaps there are fewer GPs in rural areas, with a higher patient to doctor ratio making it harder to obtain an appointment (Brabyn and Barnett 2004). Therefore the diabetes society is instead utilised for diabetes education and advice.

Important differences also emerged between rural and urban societies in relation to the sources of information that are utilised (Figure 6.7). Figure 6.7 illustrates that for

Figure 6.7: The Utilisation of Various Sources of Information by Rural and Urban Society Members



rural societies the source of information that was utilised most often was pamphlets, brochures and books (63.6%). However, for members of urban societies general practitioners were the most utilised source of information (53.4%). Rural society members used their diabetes society as a source of information to a greater extent than urban society members. A significant association was found between rural and urban societies and the extent to which members utilised the diabetes society as a source of information ($X^2 = 5.841$; $p = <0.01$).

Members indicated that the Diabetes New Zealand Magazine, *Diabetes*, and local society newsletters were useful sources of information and education. As one respondent commented: "I enjoy reading the publications...their magazine is very welcome and informative...[and the] posting out [of] monthly magazines, [as the] distance is too great (2 hrs each way) to attend meetings" (large urban society questionnaire respondent number 116). The posting out of diabetes educational information may serve to reduce barriers, for example transportation or mobility, for members who are unable to attend meetings.

Members of more rural societies utilised their diabetes society for nutritional advice, diabetes management advice and diabetes support to a greater degree than members of more urban societies. For example, 30% of rural society members indicated that they utilised their society for diabetes management advice compared with 18.9% of urban society members while 30.0% of rural society members used their society for nutritional advice compared to only 22.5% of urban members. Thus, for members of rural societies, their diabetes society is a significant provider of diabetes-related advice and support. For members of urban societies their general practitioner was the primary source of diabetes management advice (46.0%), diabetes support (26.7%), nutritional advice (26.3%) and exercise advice (23.2%). These results may indicate that the availability and accessibility of health care professionals, namely general practitioners and practice nurses, in rural areas may be limited. The lack of availability of health care professionals in rural New Zealand has been noted elsewhere (The Royal New Zealand College of General Practitioners 2002; Brabyn and Barnett 2004).

6.4 Variations Associated Within Different Modes of Organisation

Social, political, economic and cultural structures within society can shape health care services (Gesler 1991; Gesler 1992; Curtis and Taket 1996; Kearns and Moon 2002; Macintyre et al 2002; Curtis et al 2004). The structure and organisation of health care systems has the potential to influence people's health, for example, it may affect access to specific health services. Areas in New Zealand have different approaches to organising diabetes care and education which are often shaped by the wider political context (Barnett 2000a). Society A and Society B are situated within different regional health care organisation. Society A is a large urban society and is situated within a regional (Area A) health care structure that is organised in a more centralised manner. Society B is also a large urban society but is situated within a regional (Area B) health care structure that is more decentralised.

Wilson¹⁴ (2004, pers comm) argues that diabetes care and education within Area A is too centralised. For example, the structure has a strong hierarchy (Jones and Moon 1987). Therefore, diabetes care and education is organised within this hierarchy as opposed to having their "heels on the ground" (Wilson 2004, pers comm) and being embedded within the community. According to Jones and Moon (1987) a centralised network of health care involves a hierarchy of provision similar to a central place system. This relates to central place theory which argues that consumers are utility-maximising decision makers (Jones and Moon 1987; Johnston et al 2002).

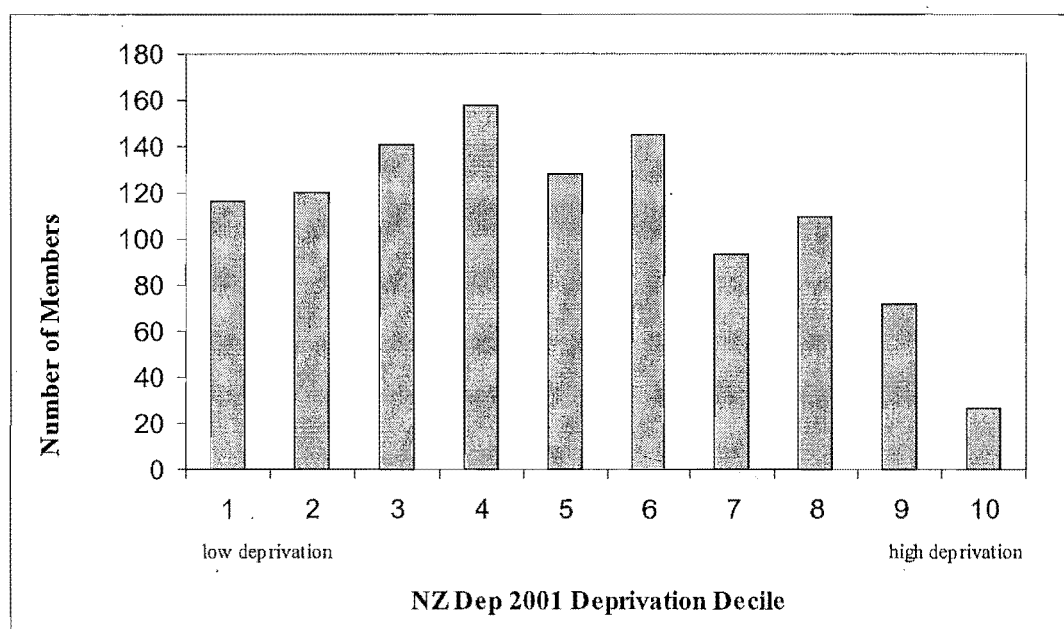
In contrast, Society B operates within a more decentralised model (Pope 2004; Wilson 2004, pers comm). Decentralisation involves the dispersal of service providers and maximises opportunities for community involvement. This model also attempts to match services to local needs. It also aims to utilise local knowledge, encourage collaboration and attempts to make services more accessible and user friendly for consumers (Pinch 1997; Curtis and Taket 1996). This section aims to examine the differences, for example, in relation to deprivation profiles, level of involvement, views of effectiveness and provider preferences, that emerged between Society A and Society B.

¹⁴ Diabetes Educator at a Primary Health Organisation in Area A.

6.4.1 Deprivation Profiles: Society A and Society B

Some important differences emerged between the deprivation profiles for Societies A and B (Figures 6.8 and 6.9). Membership in Society A is highest in deciles 3 to 6,

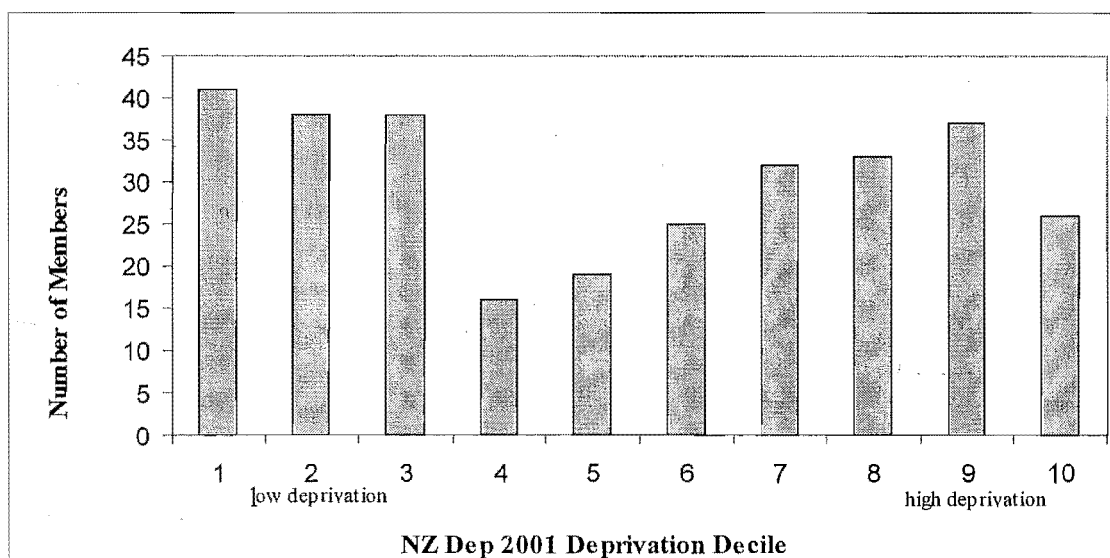
Figure 6.8: The Number of Members from Society A (Centralised) According to Deprivation Decile



with decile 4 having the highest membership number (158). Membership increases between deciles 1 to 4 and then decreases from decile 6 to 10. There are only 27 members living in decile 10.

The deprivation profile of Society B is markedly different (Figure 6.9). The highest

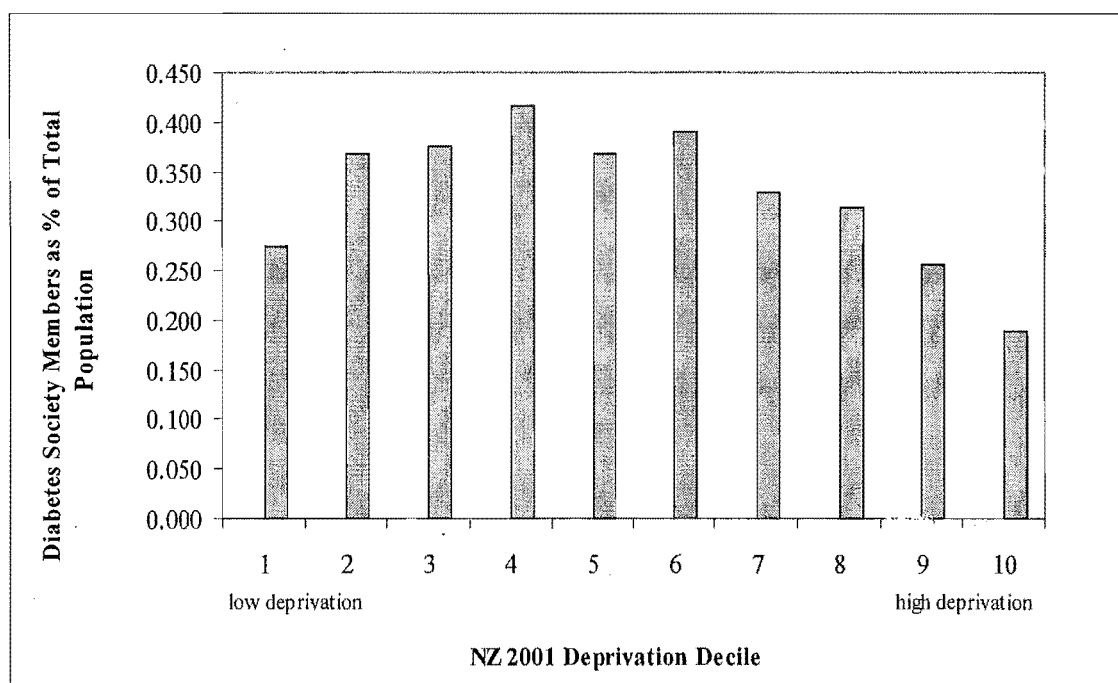
Figure 6.9: The Number of Members from Society (Decentralised) According to Deprivation Decile



membership numbers are in the lowest deprivation deciles (1 to 3). Membership increases between deciles 4 to 9 and then decreases at decile 10. Society B has more members in the highest deciles (1 to 3) and the lowest deciles (8 to 10) compared with Society A. In contrast to Society A, Society B has the lowest number of members in decile 4 (16). A decentralised structure may better suited to reach the people in the more deprived areas, the 'hard to reach', given the increased local involvement and community focus of a decentralised model of organisation.

Membership rates for diabetes society members as a percentage of the total population, using the 2001 census, by deprivation decile were also calculated. It was found that Society A had the greatest rates of participation between deprivation deciles 3 to 6¹⁵ (Figure 6.10). Participation rates are similar to the deprivation profile

Figure 6.10: Members of Society A (Centralised) as a % of the Total Population by NZ Deprivation Decile



of Society A (Figure 6.8). Figure 6.10 illustrates that participation in the diabetes society, as a percentage of the usually resident population, is higher through the middle deciles. For Society A, participation in the diabetes society is lower in the highest (9 and 10) and lowest deprivation deciles (1 and 2). Membership rates were

¹⁵ For Society A, the lowest participation rate was found in decile 10 (0.188%). Indicating that in decile 10, as a percentage of the usually resident population, diabetes society members comprised 0.188% of the population. The highest participation rates were found in, decile 3 (0.375%), decile 4 (0.416%), decile 5 (0.368%) and decile 6 (0.390%).

not calculated for Society B as society members are highly dispersed around this region, thus any results regarding rates would be meaningless.

6.4.2 Members' Perceptions of Effectiveness and Level of Involvement

Members from Society A and Society B had differing perceptions on the effectiveness of their society in dealing with increasing diabetes rates. For example, 32.8% of Society B members perceived their society to be an effective way of addressing increasing diabetes rates in their area, compared to 28.8% of Society A members. However, no significant relationship was found. Members of both Society A and B considered GPs, advertising and the diabetes societies as being important ways of address increasing diabetes rates at a national level. However, members of Society B, considered the encouragement of self-care, as a way of addressing increasing rates, to a greater extent than members of Society A (52.2% and 44.7% respectively), although again no significant relationship was found.

Members of Society B were involved with their society to a greater extent than members of Society A. For example, 13.8% of Society B members indicated being "always involved" with their society compared to only 2.9% of Society A members. Although weaker, an association was found ($X^2 = 3.434$; $p = 0.06$). Members of Society B (28.4%) also met more regularly with other people who had diabetes than members from society A (25.0%). Of those who met with other people who had diabetes, members of Society B (63.4%) were more likely to share information than members of Society A (49.2%). A more decentralised network of health care that has a strong community focus may foster member's involvement in community organisations like the diabetes societies. The greater extent of involvement with their society by Society B members may be influenced by their views on how effective they think the diabetes society is in addressing increasing diabetes rates.

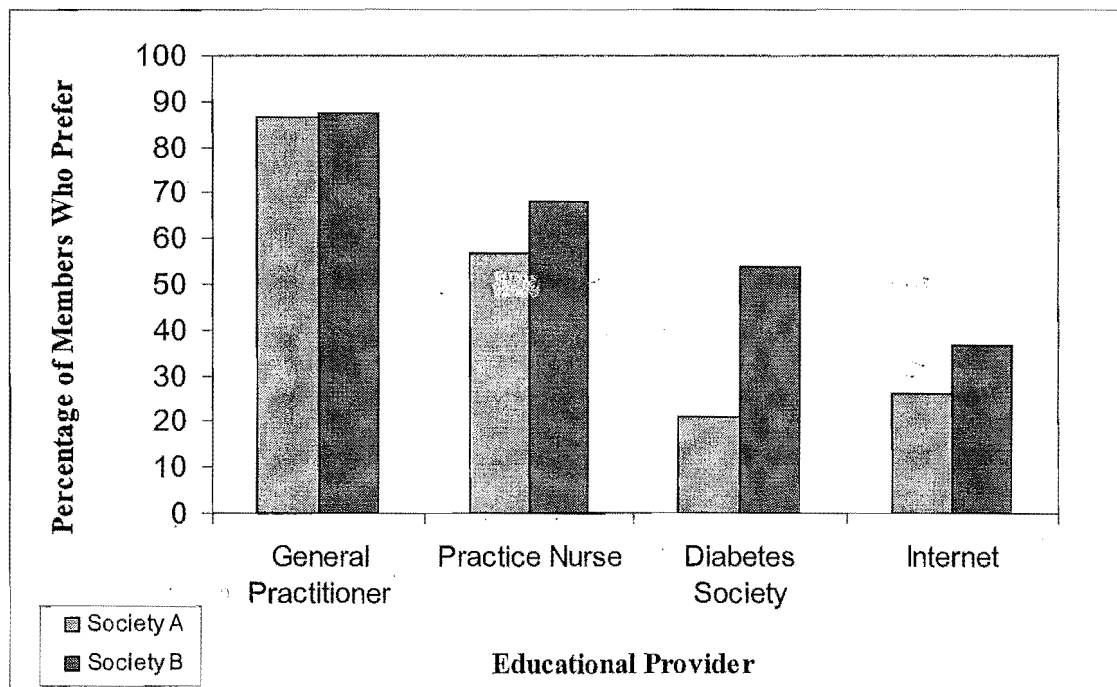
It was evident that more members of society B felt that their own membership had helped them to help others with diabetes to a greater extent than members of society A (61.4% and 38.6% respectively) ($X^2 = 7.334$; $p = 0.06$). Members from Society B (53.4%) were also more likely to talk to family and friends about diabetes and how diabetes can be prevented than members from Society A (31.6%). However, no

significant association was found. The nature and organisation of a decentralised health care network may encourage greater interaction and communication between people due to increased community involvement with health care, which in turn may increase awareness.

6.4.3. Diabetes Education

In terms of preference for various types of diabetes educational providers, several differences emerged between the two societies (Figure 6.11). Figure 6.11 illustrates that members of both Society A and Society B preferred their general practitioner as their educational provider. The diabetes society, as a provider, was preferred to a greater extent by members of Society B (53.8%) than Society A (21.0%). The greater preference of the diabetes society as a provider by members of Society B may be influenced by the fact that members were more involved with the society. Increased involvement therefore may potentially influence member's preferences in relation to diabetes care and educational providers.

Figure 6.11: Preference of Various Educational Providers for Society A and Society B



Overall, members of the two societies tended to prefer more individually based providers, for example GPs and practice nurses. The internet could also be viewed as an individually based provider as it does not involve as one-to-one consultation, it

allows people to search for information in an environment that is comfortable for them. The ability to obtain information from home may also help to reduce the effects of the stigma associated with diabetes. The presence of a stigma may also be reflected in members' preferences towards more individually based providers (Lichtenstein 2003; Schulze and Angermeyer 2003; Tak-Ying Shiu et al 2003).

Table 6.2 illustrates the level of preference and actual provision of various educational providers for members of both societies. It would be expected that members of Society B would prefer their diabetes society to a greater extent, than members of Society A, given their greater levels of involvement and this is what occurred. 53.8% of Society B members strongly preferred their diabetes society as a provider, compared with only 21% of Society A members. But even in the decentralised society more people preferred their GP to the diabetes society. Although 21% of Society A members preferred their education from the diabetes society, 62.0% of members received almost all of their diabetes education from their society. A significant association was found between preferred educational provider and actual educational provider for centralised and decentralised organisation of diabetes care and education (Society A: $X^2 = 37.352$; $p = <0.001$; Society B: $X^2 = 6.040$; $p = <0.01$). These results indicate that the diabetes society has an important role within

Table 6.2: Level of Actual Provision and Preference by Various Educational Providers for Society A and Society B

Educational Provider	Society A		Society B	
	Always/almost always provides	Strongly prefer	Always/almost always provides	Strongly prefer
Doctor/GP	65.2	86.7	61.7	87.3
Practice Nurse	35.9	56.6	56.1	67.9
Diabetes Society	62.0	21.0	56.3	53.8
Internet	8.1	25.9	15.2	36.7

the network of diabetes and educational providers, and are a significant educational provider for members of Society A and B.

Members from both societies preferred their GP as a provider than actually received education from their GP. These results may also suggest that barriers exist in terms of accessing various types of diabetes care and education exist. Barriers may relate to cost, availability or, satisfaction. The large increase in people who receive care and education from the society in relation to those who prefer it may indicate that there could be a lack of availability or satisfaction with other providers. It could also indicate that the diabetes society is a more accessible source of information and advice for members.

Members of both societies utilised individually based providers, such as GPs, as sources of information to a greater extent than utilising their diabetes society. For example, 47.6% of Society A members utilised their general practitioner as a source of information compared to only 25.0% utilising their diabetes society as a source of information. Similar results were found for Society B, with 59.3% of members utilising their GP for information and only 17.5% utilising the diabetes society for information. It also emerged that pamphlets, brochures and books were a very highly utilised source of information by members of both societies, (Society A and B, respectively, 43.2% and 64.5%). There was a significant association ($X^2 = 3.952$; $p = <0.05$) between mode of organisation and the utilisation of pamphlets. Members of Society A and B indicated that the Diabetes New Zealand magazine, *Diabetes*, and local society newsletters were also a valuable source of information.

Members of Society A utilised the services of their society to a greater extent than Society B members. For example, 22.8% of Society A members utilised their society for diabetes support, while only 17.0% of Society B members did. For diabetes management advice, 17.5% of Society A members used the society while only 13.6% of Society B members. These results were surprising given that overall, Society B members were more involved with ^{their} ~~there~~ society than Society A. These findings may suggest that the nature of diabetes societies across New Zealand varies according to different models of regional health care organisation. Such differences in organisation may influence the operation of the diabetes society. Furthermore, these results indicate that there is a complex array of factors influencing the utilisation of diabetes educational services in New Zealand. Given this complexity and that barriers exist in relation to utilising diabetes educational services the following section will

address what factors influence the utilisation of educational services in Christchurch in more detail.

6.5 Utilisation in Christchurch

To gain a greater understanding of the barriers to accessing care in Christchurch it is also important to understand what factors influence utilisation. Pegasus Health is a Primary Health Organisation (PHO) in Christchurch, approximately 90% of medical centres are members of this PHO and they hold a comprehensive data set of the population of people with diabetes in Christchurch. To investigate the factors that influence the utilisation of diabetes educational services in Christchurch a data set from Pegasus Health on the population of people with diabetes in Christchurch, along with the membership information from the Christchurch Diabetes Society was obtained. Chapter Five outlined the nature of this data.

Correlations were calculated between the percentage of people on the Pegasus Health database who were members of the Christchurch Diabetes Society and six social characteristics relating to: socioeconomic status, % Asian, % Pakeha, % Maori, and % Maori and Pacific Islanders and % of persons aged over 50. These correlations were computed for the 115 Census Area Units in Christchurch.

The results revealed that ethnicity and deprivation were the best predictors of lower rates utilisation of educational services provided by the Christchurch Diabetes Society (Table 6.3). Therefore, Maori and Pacific Islanders along with people in higher deprivation deciles had a lower utilisation of the diabetes society. However, age (50+) was the only factor related to an increased utilisation of educational services. Age, as a factor relating to utilisation, was also reflected in the questionnaire, as one of the most commonly represented groups in society membership was older aged people.

Table 6.3: Correlation Coefficients for Utilisation of the Christchurch Diabetes Society According to Different Factors

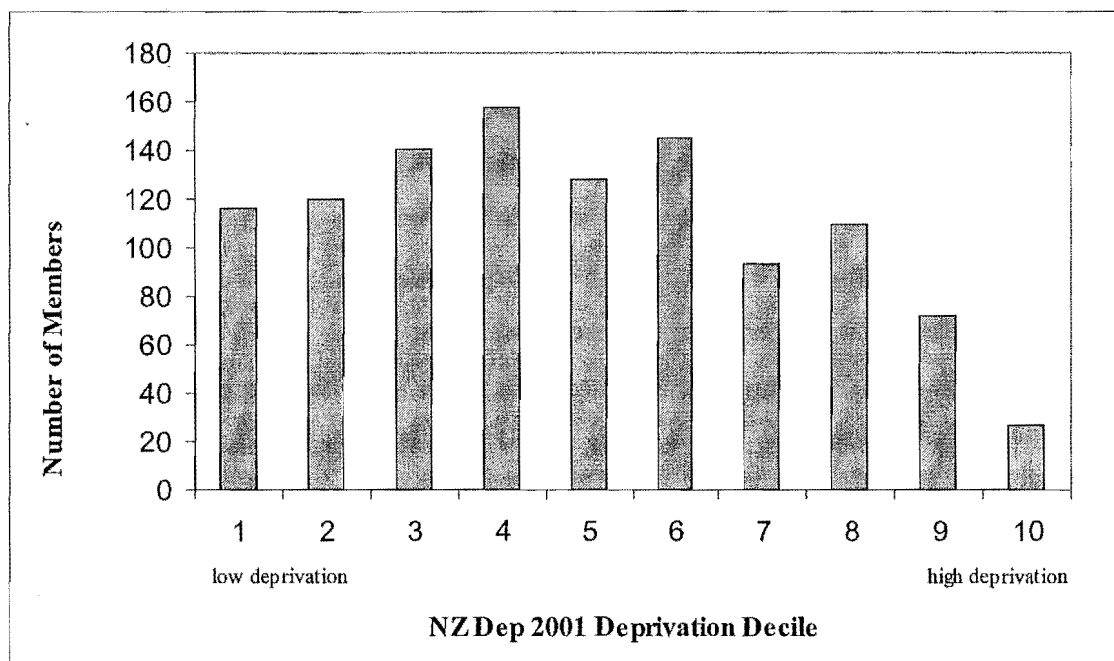
Factors influencing utilisation	Correlation Coefficient
% Asian	0.05
% Pakeha	0.06
% Maori	-0.41 *
% Maori and Pacific Islander	-0.40 *
NZ Dep 2001	-0.29 *
% Aged over 50	0.27 *

*p = <0.01

However, the Pegasus Health database does not contain all persons with diabetes in Christchurch since not all medical centres are members of Pegasus. Therefore the percentage of people with diabetes who were diabetes society members will be higher than a true figure since the denominator does not count all people with diabetes. There were also very few Maori and Pacific Islanders represented in the Pegasus data, and this may be because they do not attend Pegasus practices. However, it is necessary to investigate this under-representation to identify where and if 'high risk' groups, like Maori and Pacific Islanders, receive their diabetes education.

Using membership information from the Christchurch Diabetes Society a deprivation profile for the Christchurch Diabetes Society was calculated (Figure 6.12). The findings support the results that emerged from the Pegasus data. Figure 6.12 illustrates that there are fewer members of the Christchurch diabetes society who are in the higher deprivation deciles, suggesting that deprivation may influence the utilisation of diabetes educational services in Christchurch. The Pegasus data and the Christchurch diabetes society deprivation profile highlight that ethnicity and deprivation are important factors influencing the utilisation of diabetes care and educational services in Christchurch. Chapter Seven explores this under-utilisation and the associated barriers to utilising diabetes educational services in greater depth.

Figure 6.12: The Number of Christchurch Diabetes Society Members According to Deprivation Decile



6.6 Chapter Summary

This chapter has presented the findings from the questionnaire that was sent to members of six diabetes societies in New Zealand. The diabetes society was found to be a significant educational provider for members. Although members tended to prefer more individually based providers, namely general practitioners, the role of the diabetes society for social support was evident.

It was found that the most commonly represented group in the diabetes society membership was European, female and over 60. Overall it was revealed that there were fewer diabetes society members within the highest and lowest deprivation deciles. However, marked geographic variations exist. For example, between rural and urban societies, rural societies have a large proportion of membership within the highest deciles. Urban societies, however, have a similar deprivation profile to that of the overall profile, with fewer members in the highest and lowest deprivation deciles.

Overall, the diabetes societies were considered by nearly half of their members (44.0%) to be an effective way of dealing with the increase of diabetes rates at a

national level. Over one third of members (36.7%) considered that their local society was effective in addressing increasing rates in their area. However, geographical and organisational variations emerged. It was apparent that members of rural societies were more involved with their society and perceived it to be more effective in addressing the growth of diabetes than urban society members. Members of the society within a decentralised structure were also more involved with their society and perceived their society to be more effective in dealing with increasing rates to a greater extent than members of the more centralised society. These differences could suggest that the smaller size of many rural societies and the community focus of a decentralised network may influence encourage involvement and interaction with the society.

In Christchurch, ethnicity and deprivation emerged as being important factors influencing the utilisation of diabetes educational services. It is important to gain insight into the perceptions of these groups to understand who provides their education and if they experience any barriers in accessing diabetes care and education. By linking the objectives pertained to in this Chapter with the overall thesis aims the following chapter will further develop these results and explore in more depth the barriers associated with utilising diabetes educational services in Christchurch.

CHAPTER 7

What Stops You?

Barriers to Utilising Diabetes Educational Services in Christchurch

7.1 Introduction

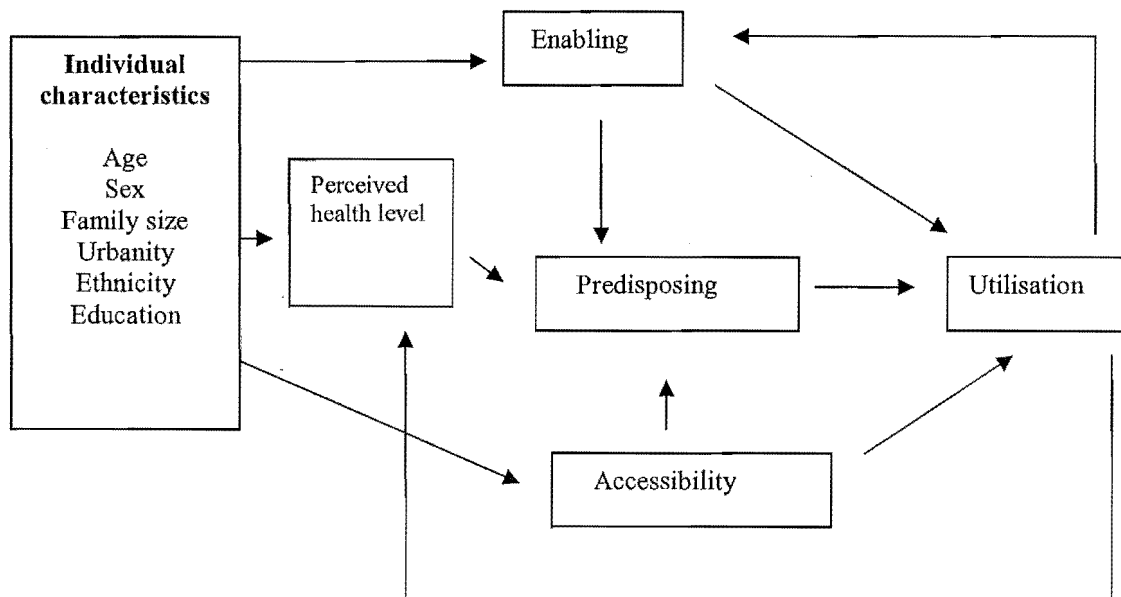
The previous chapter discussed members' perceptions their diabetes societies in New Zealand, and addressed the first research objective. This chapter will address the second research objective, to explore the extent to which diabetes educational services, like the diabetes society, are utilised. Chapter Seven, draws together data that were generated from a focus group at the Pacific Island Health Centre Christchurch and in-depth interviews with people who have diabetes from a medical centre in a more deprived area of the city. Chapter Six outlined that Pacific Islanders were under-represented in diabetes society membership. It was also found that ethnicity and deprivation influenced a lower rate of utilisation of educational services provided by the Christchurch Diabetes Society. In light of these results the aim of this chapter is to explore in more detail why Pacific Islanders and people living in a higher deprivation decile in the city fail to utilise diabetes educational services in Christchurch.

There is a limited amount of qualitative research discussing people's perceptions and utilisation of diabetes care and educational services in New Zealand. Relatively few studies have attempted to understand barriers to accessing and utilising health care from the patient perspective (Zigbor and Songer 2001). In order to gain a holistic understanding of why people do not utilise diabetes educational services a qualitative approach has been undertaken. This Chapter explores the discourses that operate within this context and how they construct meanings about diabetes care and education. However, it is first necessary create a framework for analysing barriers to accessing health care in this context based on previous research.

7.2 Traditional Models of Barriers to Health Care

There is a wealth of literature exploring barriers to accessing and utilising health care (Joseph and Phillips 1984; Anderson et al 1991; Simmons et al 1999; Glasgow et al 2001; Zgibor and Simmons 2001; Zgibor and Songer 2001; Simmons 2001; Timmins 2002;). Joseph and Phillips (1984) have provided a conceptual framework for exploring barriers to accessing health care (Figure 7.1).

Figure 7.1: A Conceptualisation of the Health Care Utilisation Process: One Possible Causal Chain.

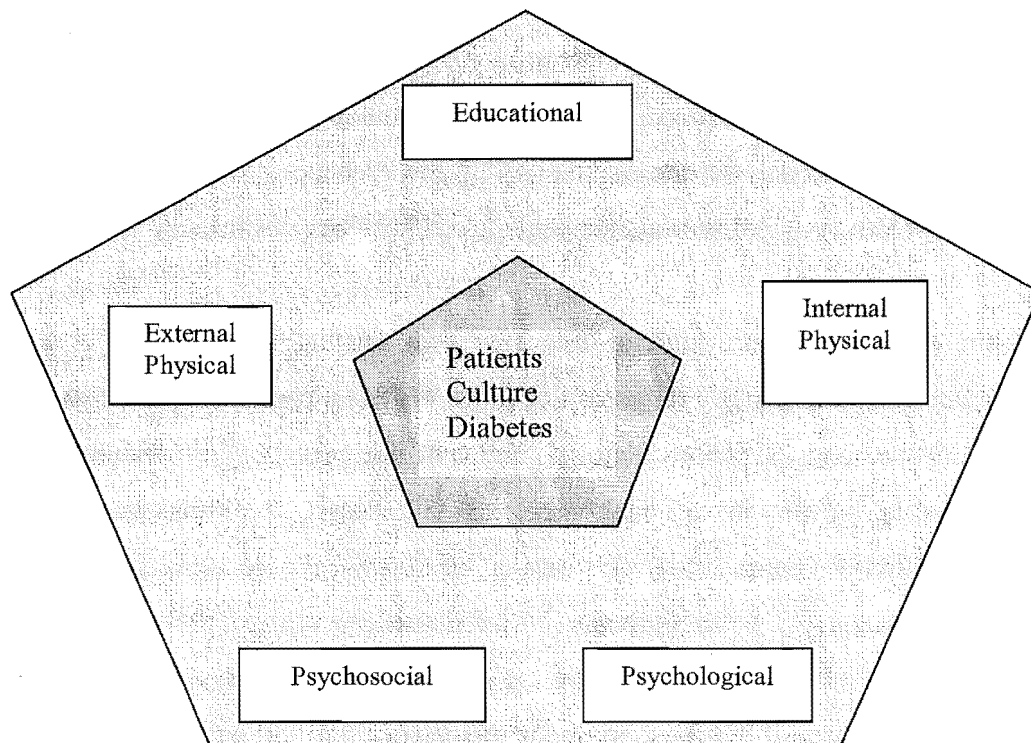


Source: Joseph and Phillips 1984, p60.

This diagram represents the multiplicity of factors that interact and influence health care utilisation. Enabling factors refer to the socio-economic barriers that may be experienced, for example, income and ethnicity. It also refers to the organisational structure of the health care system. Predisposing factors relate to behavioural and attitudinal aspects of an individual's health beliefs. Joseph and Phillips (1984) argue that the three interrelated dimensions: geographical or physical, the socio-economic, and the organisational characteristics of the health system, are important components that interact and affect access and utilisation of health care services. This model provides a useful way of considering barriers to health care. However, it still approaches barriers to health care in a linear manner. It also does not mention that dissatisfaction with the health provider may be a barrier to accessing care, along with the quality of care that is provided.

There are however various ways to conceptualise barriers to health care. Simmons (2001) presents a different framework for analysing barriers to diabetes care (Figure 7.2). Simmons' (2001) conceptual framework for analysing barriers to diabetes care

Figure 7.2: Barriers to diabetes care



Source: Simmons 2001

differs markedly to Joseph and Phillips. Simmons (2001) identifies five categories which translate as barriers to optimal diabetes care. Educational barriers relate to low diabetes knowledge and low knowledge of services. External physical or systems barriers concern, for example, personal financial issues, poor physical access to services, limited range of service availability and poor quality. Internal physical barriers may relate to the physical effects of treatment which may deter people from utilising care again. Psychosocial barriers are for example, cultural or gender-based. Psychosocial barriers may also be a lack of family and/or community support. Personal health beliefs, public health beliefs and low self-efficacy may also translate as psychological barriers. Simmons (2001) raises several important ideas in relation to diabetes care, for example, community and family support and personal health beliefs. It is important to consider these in the context of diabetes care and education. Several other authors conceptualise barriers to health care in similar ways (Coonrod

2001; Zigbor and Songer 2001; Zigbor and Simmons 2001). Quantitative techniques have often been employed to undertake such research.

Before conducting this fieldwork it was thought that issues relating to cost, transportation and language barriers would be important factors influencing utilisation. These issues were raised, for example the cost of purchasing particular products and the language and communication barriers between Pacific Islanders and Pakeha New Zealanders. However, several other themes emerged, while not exactly 'traditional' barriers to access, the results of this research provide a valuable insight into why people may not utilise diabetes educational services in Christchurch.

Several themes recurred throughout this research and will be addressed in the following sections. Although related to Simmons (2001) schema, I would argue that these findings extend Simmons' model and provide another dimension to the understanding of barriers to utilising care. This research explores the way that barriers to utilising health care are experienced by people. While Simmons emphasises the need to incorporate the views of people with diabetes in research practice, exactly how this should be achieved is not illustrated. These models do not attempt to explore these barriers in more depth or explain why they are more prevalent among some groups. The importance of a qualitative research approach to such an investigation is neglected by Simmons (2001). It emerged that ideas surrounding the body and exposing ones body to another person emerged as being very important, especially for Pacific Island women. The notion of denial of having diabetes recurred throughout this research. Fear of things foreign and of the truth were also alluded to. The issue of a stigma being associated with diabetes was brought to the fore. Another prominent theme related to people's perceptions about of diabetes care and educational providers and their preferences.

7.3 The Body

It emerged from fieldwork that Pacific Island women's bodies are conceptualised as being a very private. Concerns over the privacy of ones body and modesty in relation to undressing in front of others was expressed during this research. It could also be argued that these ideas are not only limited to Pacific Island women. According to Moss and Dyck (2003) the body can be seen as a nexus through which women with

chronic illness experience both discourses and materialities of the ill body. Making sense of women's experiences with illness entails a close reading of meanings ascribed to particular experiences. These ideas are relevant to the context of this research because the way that people handle their bodies over time and space reflects the interplay between place, gender and health (Moss and Dyck 2003). Such an exploration may provide insight into the complexities surrounding utilisation of diabetes care and educational services in Christchurch.

Exposing ones body was a very real issue for Pacific Island women and appeared to be an important barrier. In relation to this, Karen, a participant from the focus group at the Pacific Diabetes Support Trust, comments that:

...I'm talking about Pacific Island women, [they] have never ever allowed anyone else to see their bodies except their husband and this is a reality. When they're asked in front of a doctor to undress it's nothing to do with the doctors or with anybody, but when you're exposing yourself in front of a total stranger to tell you about your illness something is wrong I would rather walk away with that feeling than having to stand in front of a doctor and ah undress myself. It took me a long time a very long time before I could stand in front of my own doctor to whom I have known all my 6 children, there's many maybe negative things, but real things, they are real to us....

Karen's comment clearly illustrates that health care is an embodied experience. By stating that she would "rather walk away with that feeling than undress" reinforces the sense of fear or anxiety that may be present when exposing ones body or talking about personal issues. This finding is consistent with Moss and Dyck's (2003) assertion that health is experienced through our bodies. It also reveals an interaction between conceptualisations of the body and health beliefs. The use of the word "expose" has connotations of vulnerability and bringing to public notice, which may reinforce feelings of fear and discomfort. Feelings of anxiety and fear may also influence people's health behaviour. Karen's comment also highlights that Pacific Island women may feel less comfortable with male health professionals, especially in relation to talking about personal and private issues regarding to their bodies. The private nature of Pacific Island women's bodies is also reinforced.

One thing that struck me during the focus group was that even though Karen had never met me before she felt more comfortable talking to me than with her heart specialist whom she knew, but he was a man. This represents an important cultural value in relation to Pacific Island women talking about personal and private health issues and their experiences in sharing these with other women and men. Karen comments that:

...I'm ok with you because you're a woman. I can sit and talk quite openly, whereas with Mr Smith, the heart specialist it takes a blimmin' half an hour for him to wait for me to talk. I thought well somebody's got do a conversation here and I looked at him and I says are you hungry, just to break the ice and more often than not I'll take in an apple and say here you are, you eat while I talk sort of thing, isn't it terrible um [laughs] ...it is because I come to know the man who saved me [and] I still have a fear in my mind...

It is also interesting that Mr Smith¹⁶ is not only a man, but he is also an authority figure. This status may also influence Karen's feelings of anxiety. This comment reflects Foucault's assertion that the creation of expert knowledges about human beings and health serve to channel and constrain actions, behaviours, beliefs and experiences in the health care environment (Foucault cited in Petersen and Lupton 1996)

7.4 Denial and Fear

It emerged from this research that denial is a very real issue for people with diabetes. Fear and anxiety are also associated with denial. Denial is a common coping strategy adopted by individuals until the implications of having a chronic illness can be accepted (Olney et al 2004). It is important to recognise denial due to the insidious nature of type 2 diabetes and the severe complications that can result if left unchecked (Belchetz and Hammond 2003; Farmer et al 2004). Several of the participants indicated that it was not until something serious happened to them or to someone they knew that diabetes became a reality. This idea relates to the insidious nature of type 2

¹⁶ Mr Smith is a pseudonym that will be used throughout this thesis.

diabetes. Type 2 diabetes may only be diagnosed after a heart attack or stroke, even though it may have been present for several years (Barnett et al 2001). The nature of type 2 diabetes was discussed with more detail in Chapter 2. The idea of being shocked by diagnosis also alludes to peoples' conceptualisations of risk. Karen comments, that:

...now the seriousness of diabetes alerted um the minds of the Pacific People when there was just one after another person not so long ago who died with diabetes. That impacts the way we think and the way we recognise and the way we respond, and ah now we're getting very serious with it. I was told by my doctor if only I stayed a bit longer I would have died, because 11.7 ahh very high sugar in my body. It was an infection in my blood...but that really gave me something to think about [speakers own emphasis]...

John expresses his disbelief regarding his diagnosis and denies having diabetes until viewing the test result, he comments that:

...they sort of did the testing and said that I've got diabetes. That was the first I, I said I don't believe it, until they showed me the ah results and said really, I had to ask again it's just beyond me...I just couldn't believe it [speakers own emphasis]...

John's comment also relates to his conceptualisations of risk. Given his disbelief he may never have considered being at risk from diabetes. Knowledge and awareness of diabetes along with personal health beliefs are also important here. Being unaware that you may be at risk from diabetes has implications for the nature of information that is disseminated from health professionals and public health offices. The disbelief expressed by John may also be reinforced by the insidious nature of type 2 diabetes.

Joanne further illustrates the issue of denial:

...um it takes time to accept... I've seen a lot of people who've been given a lot of information and I've seen people in the centre, you've seen them about 4 times, sent here by their GPs cos they've got diabetes. You've talked with them at least twice and they get admitted maybe a year later,

and they tell the other person they didn't know they had diabetes so y'know...

Joanne's comment illustrates that denial is something very real for Pacific Islanders. However, the notion of denial may not only be limited to Pacific Islanders. Upon admission to hospital the 'reality' of having diabetes becomes more real. This realisation may be related to the symbolic nature of hospitals as being places where people who are ill go to be healed. This idea may also be related to fearing the truth or the unknown. Joanne's comments may also relate to a potential communication failure between health providers and patients.

The comments above from Karen, John and Joanne also highlight the notion of risk and the associated risk factors of diabetes. People conceptualise ideas of risk differently. In John's case, diabetes may not have been a 'reality' for him until he was shown the results for a second time. Whether it is the fear of being diagnosed or the lack of awareness that may lead to denial it is important to consider these issues and how they influence health behaviour.

Denial of the seriousness of diabetes was a recurrent theme throughout interviews with people from a medical centre in Christchurch. Patricia and Sarah mentioned, respectively that they 'only' had type 2 diabetes and as such did not feel they were that bad:

...at the moment um don't feel I'm bad enough...I mean I don't feel as though I'm ill or anything like that...I've only got diabetes 2 you see, I don't feel that I'm bad enough...(Patricia)

...I'm not that bad, I mean I'm only type 2 or whatever....(Sarah)

Both women remarked that having type 2 was in some way less serious. When asked why they did not think they were bad enough, neither Patricia nor Sarah elaborated. It was reinforced however, that they were not ill. By stating that they are not ill may be a way of coping with and accepting the severity of type 2 diabetes and the associated complications.

Patricia and Sarah were both treated with tablets, diet and exercise. Their perceptions of not feeling ill or bad enough may be related to their association of diabetes being more serious when a person is on insulin. Patricia commented that:

...my sister in-law was really bad...she had injections, and y'know she'd pass out and all sorts of things.

These comments also illustrate that some people, even those with diabetes, may often be misinformed about the seriousness of type 1 and type 2 diabetes and the associated complications, which can be fatal if neglected. Such ideas have implications for levels of awareness of diabetes among the community and levels of knowledge and understanding among people who have diabetes, thus the importance of diabetes education.

Much research indicates that people underestimate their personal probability of encountering negative health events (Olney et al 2004). Ideas of denial may also be related to conceptualisations of risk, and whether a person believes they are at risk. During the interview participants remarked that they had not thought about developing diabetes or being at risk:

Researcher: *so before you were diagnosed with diabetes did you think that you might have been at risk?*

Patricia: *No, not at all didn't think about it...I think I thought that I'd got to the age I am without it that I wouldn't get it. In fact I'd said to somebody just that, oh I won't get diabetes now, and then found out a month or so later.*

Sarah: *No didn't even think about it.*

These comments illustrate how people perceive and conceptualise risk and their awareness of the risk factors associated with diabetes. The conceptualisations of risk that are given by Sarah and Patricia may also be related to ideas of denial. It is interesting to note that both Patricia and Sarah knew people who had diabetes, in Sarah's case family members, but did not believe they themselves were at risk.

Understanding people's perceptions of risk in relation to diabetes is important when investigating barriers to care. As Patricia, Sarah and others illustrate they did not think they were at risk of developing diabetes, therefore this would be less likely to seek medical advice.

The observation that there is not a name for diabetes in some Pacific Islands may influence the way diabetes is conceptualised and responded to among Pacific Island communities. In turn, such conceptualisations may influence individual health beliefs and foster feelings of fear. In relation to his diagnosis John states that he:

...had been quite healthy, been ah very active in every sport, and then I never had this when I was in Samoa...diabetes is a foreign illness...we don't have a name for it do we.

Diabetes was framed as a foreign illness, which constructs it as something that is not 'natural' for Pacific Islanders. The framing of diabetes as 'foreign' may manifest feelings of fear, influencing community and individual health beliefs. These feelings in relation to diabetes may then be disseminated within communities and as such may translate as barriers to utilising health care. It may also influence different cultural understandings of health, health care and health behaviours.

Fear and anxiety in relation to things foreign and fear of the 'truth' were expressed by participants. It was seen as something very real for Pacific Islanders. Karen's comments highlight this fear:

...even though I [have] lived here for nearly 50 years I fear anything that its foreign to my face...scared yeah...I'm still very frightened when I go to see a heart specialist cos I don't want him to tell me...

This idea was expanded on by Joanne and Karen who assert, respectively, that:

...the fear of the truth and fear of anything that's foreign to us lot, machinery and even the clinical look. Wonder what the doctor's gunna do and what he's gunna say to you and what he's gunna tell me. I think that's

a very real thing...I think that um the information may be out there but that fear can stop you from actually receiving the information...

...I was terrified...fear of the truth, fear of the unknown, those are the two things not just for me. Cos we were not exposed to those things as we were growing up. Until we walked away from the herbals, the soothing of the mother praying to you, praying about you and then you saw these machines and then an answer came back...

Karen also expresses that fear can act as a barrier to receiving information:

...I still have a fear in my mind, and ah I don't really know why, maybe cos it was never exposed to be a healthy person like what John says. To be a healthy person until you come to the stage that something's wrong with you. You build the fence around you and that block around you, nobody's going to touch you.

Karen's comments regarding building a fence around you and Joanne's comments above regarding fear acting as a barrier provide an insight into why some Pacific Islanders may not utilise diabetes care and educational services in Christchurch. The prominence of fear of the foreign and fear of the truth may be related to the idea of denial about having diabetes, especially if this fear acts as a barrier to receiving information.

The above comments bring to the fore some very important issues for Pacific Island peoples. Karen stated that even after 50 years of living in New Zealand that her fears of things foreign were still very prominent. Many Pacific Islanders may not be socialised into an environment where Western medicine and technologies are normalised. Many Pacific Islanders may not have been exposed to the 'clinical look', for example, high-tech equipment or medical jargon and may be afraid of this environment. However, many people who are exposed to the clinical environment for the first time may experience feelings of fear. For some Pacific Islanders who may have relied on herbals and prayer for healing there may be an additional layer of foreignness.

Furthermore, this fear alludes to the idea that the medical environment in the Pacific Islands and people's experiences and interactions with it differ from that in New Zealand. For example, public health nurses often deliver health care to people in Samoan villages free of charge (Saau 1996). Traditional and home remedies, for example herbal medicines and oil massages, are an important element of health care in Samoa. The differences in the health care environment between New Zealand and the Pacific Islands may lead to feelings of fear among Pacific Islanders, thus a barrier to utilising health care. These differences also illustrate different ways of knowing and understanding health and health care.

In relation to this Liz a stated that:

...it's in the name as well. It's the real name it's not your family GP it's a heart specialist, it's a person dealing with diabetes, that's specifically the thing you're there for...when you go and see a specific person for a specific thing that's when everything hits home...

Liz's comments illustrate that the name or title of the health professional also influences the degree of seriousness. In a sense, it produces a situation where the severity of the issue at hand can no longer be denied. It could also serve to instil fear within people, as the diabetologist or heart specialists may appear intimidating and foreign both literally and metaphorically. People may be afraid or deny having diabetes due to the associated stigmatisation. For example, people may fear stigmatisation due to the association of type 2 diabetes with obesity (Wolfer 2003).

7.5 Effects of Stigma

From the survey results it was found that only 34.2 % of members met regularly with other people who had diabetes and shared information. These results may indicate that people feel uncomfortable talking about their diabetes or that a stigma exists. It emerged from the qualitative research that there is a stigma associated with diabetes. For example, Karen commented that:

...nobody wants to go and say ohh I've got diabetes. Nobody wants to say that...

Joanne also illustrates this theme:

...no one wants to go round saying I've got diabetes, I mean it's a huge thing to have to process to yourself...

It is vital to consider the effects of stigma as it may influence people's attitudes to seeking health care and advice. The idea of a stigma associated with diabetes also recurred throughout the interviews with the presidents of the diabetes societies throughout New Zealand. For example, the president of a rural society commented that people were worried their job may be in jeopardy if their boss found out they had diabetes. People were also worried about being questioned over eating a cake in front of people if they knew they had diabetes.

Patricia stated in relation to talking about her diabetes that:

I don't mind. I don't tell them unless they ask [laughs]. I don't go around saying I'm a diabetic [laughs].

Talking about diabetes with others was not as problematic for people from the medical centre in Christchurch compared with people from the Pacific Island Health Centre, which illustrates the point that the stigma associated with diabetes may be experienced differently among various groups. Conducting qualitative fieldwork at the medical centre in Christchurch was interesting in that only older females responded to requests for participants. This response may indicate an important gender dimension in relation to sharing information and talking about diabetes. Namely, the non-response by males may suggest that stigma is experienced differently in males and females. The nature of diabetes society membership also illustrates this as there are more female than male members, as discussed in Chapter Six. These findings reflect several assertions that involvement in voluntary organisations is more common among women (Putnam 2000; Daniulaitiye 2004 among others). The stigma that is associated with diabetes may be experienced differently among males and females. This experience may also relate to different

ages. For example, the stigma associated with blood glucose testing and “shooting up” in a school environment may increase the effects of stigma due to the association with intravenous drugs (American Diabetes Association 2003; The Child Advocate 2003).

Participants also expressed that they talked about diabetes differently in different places and situations. Contrasting discourses may then be constructed in different places. This is also related to the association of a stigma, as participants did not want to talk about their diabetes in more ‘public’ places. For example, Karen states, in reference to a consultation with her heart specialist, that:

...so y’know there’s some things we can talk quite openly and some of the things we are very selective the way we approach and how we do approach...

During the focus group at the Pacific Island Health Centre it was expressed that there is a particular way of addressing diabetes among Pacific Islanders, Joanne comments:

...it’s exactly as [Karen] said I can’t just go to John, so how’s the diabetes today [everyone laughs and shows signs of agreement]...

Karen identifies this as being very real for Pacific Islanders:

...yeah they are real and ah y’know Pacific Island people will not talk a lot about, but you know they have diabetes and you don’t talk. I’m sure when she [the diabetes nurse] goes to follow up a patient she doesn’t ask “how’s the diabetes”, she will go around that and bring the trust first in confidence before asking how are you today...

These comments illustrate that different cultural contexts and values influence the way health and health care is conceptualised and subsequently responded to. Different cultures have different ways of knowing and understanding health and health care. Therefore, it is necessary to consider these ideas when considering why Pacific Island peoples tend not to utilise services like the diabetes societies. Karen’s comment also exemplifies the importance of having trust between patients and

providers. Building trust within the relationship is essential in order to encourage matters to be talked about in a comfortable and open way

7.6 Perceptions of Diabetes Care and Educational Providers

Throughout this research, various perceptions of diabetes care and educational providers have been expressed. It emerged that Pacific Islanders have very different perceptions of diabetes care and educational providers from participants at the medical centre in Christchurch. Three key themes recurred throughout the qualitative fieldwork and will be addressed in the following section. First, the role of the family was emphasised during the focus group at the Pacific Island Health Centre, social support was also identified as being important by participants at the medical centre. Second, varying perceptions of health professionals and providers were expressed by participants. Third, the notion of empowerment recurred throughout the focus group at the Pacific Island Health centre.

7.6.1 The Role of the Family and Social Support

A primary role of the diabetes societies in New Zealand is to provide social support, as discussed in Chapter Six. However, there are other networks than can provide social support, for example the family. As such they take on an important role and further illustrate the importance of social support as an integral part of diabetes care. The family and extended family structure could be seen as a social support network.

People from the Pacific Island Health Centre placed a great value on the role of the family for diabetes care and education:

The families, I don't think any organisation can provide care the way the family does. It is because the family saw the changes within the structure and they take it into their own hands as being responsible... (Richard)

Karen also states, in reference to John, that:

...it's about how the family understand the illness within the family and how that family will support. To me, the agencies are only for information and access to other things, but it's the family. For instance [Karen gestures towards John] his own family looks after him and he looks after himself. He doesn't need anybody to say to him that you got diabetes therefore I'm coming to look after you. He looks after him, his own family looks after him and so as the people who surround him who know him well.

These comments demonstrate the value that is put on the family and highlight its key role in providing care and support for people with diabetes. It is illustrated that the family provides a feeling of familiarity as "they know you". Within such relationships there would be feelings of trust, which may encourage people to talk about private and sensitive issues. The sense of trust and familiarity may also serve to reduce feelings of anxiety and increase feelings of comfort when talking about sensitive issues. The emphasis placed on the family network may help to understand why there is a low utilisation, by Pacific Islanders, of the Christchurch Diabetes Society. Alternative values and ways of understanding health and health care delivery must be considered and understood when addressing the issue of diabetes and diabetes education. It also highlights the need to educate and increase awareness among the network of family and friends as they are the carers at home.

The role of the family was perceived differently by Patricia, from the medical centre in Christchurch. For example:

Researcher: *so do you get support from your friends and family?*

Patricia: *not really, all they do is ask if I'm alright [laughs] so that's not much help...*

This comment illustrates the values that different cultures place on the family and shows how cultural values can influence health beliefs and behaviours. There are various ways that people can receive social support. Although not provided by the family or through the diabetes society social support was seen as being important for participants from the Christchurch medical centre. In relation to social support Patricia states:

Yes, yes, we go to what we call happy hour. The old people's place around the corner, have that once a week. It's amazing how many ladies there are, at probus, who are diabetic. We find out when we got out to lunches together you see and they sort of look at you, you're not supposed to be having that [laughs]...that's right in fact you can laugh about it. There's two of them who have to inject themselves and we have quite a joke about it all actually...which is just in well.

Yes, [it is] surprising actually how many people have got it [diabetes]...I've got a friend she lives a couple of streets away and she'll ring occasionally and say do you want to go for a walk. So I always do, I ah...if she does that then I go, but if I'm just here by myself I find it hard to make myself get moving. (Sarah)

It is seen, by these participants, to be important to share information and laugh about having diabetes. In a sense the informal and comfortable environment that is constructed may help people feel that they are not alone. It may also help people accept and come to terms with their diagnosis. Furthermore, doing activities with another person or in a group may encourage increased activity which would help with diabetes management. Again the importance of social support for diabetes care and education is illustrated.

7.6.2 Health Professionals and Service Providers

Participants from the focus group at the Pacific Health Centre placed a strong emphasis on group and communal education and the role of the family. However, as with members of the diabetes societies participants from the medical centre in Christchurch preferred one to one diabetes education. Sarah, June and Patricia's comments regarding their practice nurse illustrate this preference:

...one on one with Mandy [practice nurse and diabetes nurse educator at the medical centre]...I don't think I'd like to go to a group...I would maybe get a wee bit panicky, y'know...I'm not really that bad you see. (Sarah)

...I've never been to a group session it's always been a one on one. (June)

...one on one with Mandy...I don't think I'd like to go to a group I'm not that bad... (Patricia)

These comments illustrate and provide insight into why group education is not preferred. All participants stated that they were very satisfied with the care and education they received from their medical centre, particularly Mandy, the nurse, who they felt they could contact extra advice any time. The reliance on the practice nurse may also relate to Karen's comments regarding feeling uncomfortable with her heart specialist, Mr Smith, as he is an authoritative figure. Participants expressed feeling more comfortable with their practice nurse than their general practitioner. This preference may be related to the general practitioner being in a position of authority. Sarah commented, in regard to her general practitioner that:

...I prefer Mandy to my GP because...they'll be looking at the screen while they're talking to you, and somehow you get the feeling that [they, the GP] want to rush you out...I'm able to talk it out with her [Mandy] but I can't with the doctor.

When discussing with participants about asking further questions Patricia commented that Mandy was the person she would most often utilise:

...the doctor doesn't have anything, [they have] never said anything really about it [diabetes], just referred me to Mandy

Researcher: *so who has told you most about your diabetes?*

Patricia: *Oh Mandy would have.*

June also noted in relation to when she was diagnosed:

Back then you didn't ask your doctor questions like that [laughs] ...ah you just sort of accepted what they told you...

Although June stated that she asks questions now, the ability for patients to feel comfortable asking their general practitioner questions is an important issue to consider. The President of a rural diabetes society also commented that:

...our primary group is elderly... it scares me, because there are lot of these people [elderly people] that live alone and don't have the ability to um speak up. They go to their GP and they sit there like little wee mice and it frightens me a bit that these people are so easily, well not bullied, but um, pushed aside...

These comments raise an important issue relating to patient provider relationships. For example, how expertise plays a vital role in the modern system of power and knowledge creation. The underlying dualisms often associated with health, for example, healthy/unhealthy, clean/dirty and subject/object, are also a way through which existing power relationships between patient and provider are sustained. Such a dualistic ordering can affect people's sense of identity, and their place in the world (Petersen and Lupton 1996).

Some participants from the Pacific Island Health Centre mentioned that health professionals were threatening. When asked why or to comment on this, Liz stated in relation to health professionals:

...unsupportive because they're not actually listening to the people that they need to listen to. They aren't listening or trying to understand what they're saying because there's too many technical terms to understand mainstream. You gotta remember the people who have diabetes are normally elderly, are um very little English speaking at all, not like speaking but understanding...because mainstream, to me, looking New Zealand born [you] aren't making the effort to go that extra mile to educate them in a way that they understand... I don't think you're threatening, you just don't understand and you [speakers own emphasis] don't seem to communicate well.

This comment illustrates several important issues. The environment that is depicted by Liz's comment, may foster feelings of discomfort on the part of the patient, increasing the likelihood of them not returning. Furthermore, there seem to be language and communication barriers between Pacific Islanders and health professionals, which may also influence health care utilisation. The language barriers

are not only due to some Pacific Islanders speaking little English but also in relation to the highly medicalised terminology that is used. This terminology may create feelings of anxiety within patients, especially if they do not have a full understanding of English, which in turn may influence health care utilisation.

The language barrier is compounded by the issue of time. Karen emphasised this:

...because if the time is given to you 10 minutes what can our old people do with 10 minutes. They were still struggling [with] how to respond to you with what you want to know when you ask a question. So that's another thing that's a hindrance to us is the time limit of specialists that's given to our people.

Shorter consultation times, along with fears and anxieties about the foreign environment and talking about ones diabetes initially, there may be an added layer of barriers to utilising health care for some Pacific Islanders. These comments also illustrate that different cultures have different ways of knowing, understanding and approaching health and ill health, such issues must be taken into consideration in the context of diabetes care and education.

Liz highlights the importance of trust in patient/provider relationships:

...it's not a matter of favouring Pacific Island people it's looking at your stats and saying they've got a high percentage of this, this is what they're coming in for. It's these two things getting their trust first and being culturally sensitive to their needs and getting that information across...and them [Pacific Islanders] not being scared of receiving the information that they need. It's the trust, because it doesn't matter whether they're familiar with a white or a brown face you still gotta have that trust. Like in Mum and Joanne and John's day it wasn't a thing, y'know just like us it ok, ok go and have an examination it's normal but its not the norm for them.

This comment illustrates that people cannot be isolated from their social and cultural environments when issues of health and health care are being addressed. For example, Liz's comment that "to have an examination is not the normal" for some

Pacific Islanders illustrates that the health care environment they may familiar with is markedly different from the one that they are exposed to in New Zealand. Such differences may also be found within other ethnic groups who have migrated from their ancestral lands.

Joanne and Karen also comment, respectively, about the idea of trust and different ways of understanding health care:

...that's where we're disadvantaged a lot [of people] are left [out] unless there's someone who's culturally sensitive, who has the time, which we know lots of doctors don't, y'know it's this busy world...y'know that trust thing from health providers...

...to be more sensitive towards their ah sense of knowledge and understandings...

Again, these comments illustrate the notion of the length of consultations and the importance of having a trusting relationship. As Liz states it is vital to recognise that Pacific Islanders are at an increasing risk of developing diabetes and getting the information across is of utmost importance. However, building trust is an integral part of this process and must be viewed as such. Gaining insight into cultural ways of knowing and understanding health care and how these discourses construct and influence perceptions of health and health care is important in the context of diabetes care and education for Pacific Islanders in New Zealand.

Joanne asserts, in relation to health professionals that:

...I feel if the information is coming from us [signs of agreement from other people] then it's likely for other people [Pacific Islanders] out there to feel more supported and probably less threatening than health professionals...hammering from their end. I mean we didn't really need them but there needs to be a different partnership isn't there...

The use of the word hammering in the above comment has connotations of messages being repeated, which some perceive to be unnecessary, as illustrated by Joanne.

These comments also indicate that some Pacific Islanders may find health professionals threatening and that their method of delivering information may in a more prescriptive manner. Furthermore, Karen argues that Pacific Islanders know and understand Pacific Islanders, and change needs to come from the inside rather than being imposed from the outside, hence a more grass-roots approach.

Having information home delivered was perceived to be very positive. It also reduces barriers in accessing information. For example, June mentioned that she had recently had surgery and that mobility was a barrier to accessing services. Furthermore, Sarah mentioned the increased cost of buying food at the local supermarket along with the initial cost of purchasing a blood glucose meter as she was not on a community services card. June and Sarah also comment, respectively, that:

Oh yes I get the magazine um from the advantage people, yes they have a lot of informative things there. (June)

...Roche is giving free tests down at the chemist shop and ah they gave you read outs and what have you, apparently we can to the chemist ahh any time we like and have our meters read...and that's for free...(Sarah)

This comment brings to the fore another key provider, Roche Diagnostics. Roche is a global corporation aiming to innovate health information by supporting customers in education and training (Roche Diagnostics 2002). Roche also provides Extra Care, specialising in diabetes products and services, for example Advantage meters. Extra Care is operated by Roche and manufacture specific diabetes related products. People who have become members of Extra Care can have information and products sent to their homes. Sarah asserted that:

Roche is marvellous, the people I bought the meters and that from they're wonderful...oh they send me things, they send me letters and then I also send for um new needles... I send away for some of the food its quite good...I like sending for food cos its awfully difficult to find in the supermarkets and they're jolly expensive in the supermarkets whereas I get a bit of a discount...

The sending of information to peoples' homes, in a sense, may encourage self-care and self-monitoring. It may also give people a sense of empowerment as they are taking control of their own diabetes and taking control of learning new information via magazines. However, this may exclude those who do not read English.

7.6.3 Empowerment

Another theme that recurred throughout the discussion was the notion of empowerment and becoming part of the solution. The notion of empowerment was very prominent throughout the discussion at the Pacific Health Centre. However, it was not as prominent throughout interviews with people from a medical centre in Christchurch. Joanne argues that:

...we need to have it in a venue where it's non threatening...where everybody is learning together and not being isolated as having this or having that. I still see that as a thing I mean people put up with information because you have to and because you're scared into it...our challenge is to find a way where everybody learns together in the same and non-threatening environment...

The importance of communal and group learning helps to create an environment where Pacific Islanders can take control of their own learning rather than being "scared into it".

Participants acknowledged throughout the discussion the need for Pacific Islanders to be pro-active and be in control of "their diabetes":

*...I think now we are more aware the danger of what diabetes can do to us, um and also for us as Pacific People to take control of decision making rather than waiting for somebody else to say because you have diabetes I'm going to do this to you and you will go to but because I have diabetes **I am now in control and I know** [speakers own emphasis] what to do so that's really the thing we are wanting to claim, is allowing Pacific Island People ah who live in danger of diabetes to be able to come out and say hey hey hang on...I'm the one who have the diabetes, yes I need your help but allow*

me to make a decision on it. And that's something very powerful for us as Pacific People... (Karen)

...if the door is open you've still got the power to come back and say oh I'll do something about it now...it's here what um we can do for you and its up to you, like you're saying give the power back to them to make that decision... (Joanne)

Karen also states that:

...we made mistakes we are the only ones who are going to correct those misstates, by proving to ourselves that we can master it and it's because we want to change not because somebody else tell us to change... Who knows how Pacific Island Peoples cook their food...who knows what they eat, only Pacific Island People...

Being able to make informed decisions and, in a sense, claim ownership to “your diabetes” is a very powerful thing. Allowing the person with diabetes to take control over their learning and implement changes within their life may foster a more encouraging and positive environment for ones health. Karen states that Pacific Islanders know and understand Pacific Island ways. Therefore an approach where change is driven from the inside rather than imposed from the outside is needed.

*...for 50 years we live in this country always a problem now we want to be part of the solution so we can have those informed decisions as far as we're concerned...we need to protect our children. If the survival of the Pacific community is to live a longer life for our children we need to get into this place now and try and combat...**we've got to come out and say yes we need help** [speakers own emphasis] *not like before, we'd sit and wait. (Karen)**

Empowering Pacific Islanders to take control of their diabetes is a vital step towards creating awareness and reducing diabetes rates in the Pacific community. The concept of empowerment is prevalent throughout the health promotion literature, as outlined in Chapter Three. Empowerment can be related to individuals or communities, working together to build trusting relationships and supportive

environments. It is thought that empowered communities can result in empowered individuals (Bunton and MacDonald 2002; Tones and Green 2004). Empowering people and communities and encouraging a proactive approach to learning about diabetes is one way in which medicine can be brought out of the clinical environment and into homes and communities to achieve better health outcomes.

7.7 A New Model for Analysing Barriers to Health Care

This chapter has presented several insights into why people may not utilise diabetes educational services in Christchurch. The main themes that recurred throughout this research related to perceptions of the body, specifically among Pacific Island women, and how the conceptualisation of the body as being 'private' acted as a barrier to utilising care. The notions of denial, in relation to having diabetes and the association of a stigma with diabetes were also illustrated. Both of these ideas can lead to feelings of anxiety and as such may act as barriers to utilising group education and may account for the preference towards individually based providers that was seen among people from the medical centre in Christchurch. Differences in perceptions of diabetes care and educational providers also arose. Pacific Islanders tended to prefer a more communal environment and emphasised the importance of the family as a diabetes carer. However, people from the medical centre tended to prefer care from their practice nurse. These differences illustrate different ways of knowing and understanding health and health care. The idea of having diabetes care and education that is developed from within communities rather than imposed from the outside was also emphasised. A more grass-roots approach would enable people to take control of their diabetes, fostering empowerment within communities.

While there were some similarities with the more 'traditional' models to analysing barriers to care (Joseph and Phillips 1984; Simmons 2001), several other barriers to utilising diabetes care were identified throughout this quantitative and qualitative research undertaken in this thesis. Chapter Six discussed the influence of different models of health care organisation, rurality and deprivation, through the deprivation profiles that were presented, on diabetes society membership. It was found that these factors had a significant influence on society membership. These findings are consistent with Joseph and Phillips (1984) assertion that geographical or physical,

socio-economic and the organisational structure have an important influence on the utilisation of health care services. Furthermore, Chapters Six and Seven illustrate the importance of social support for people with diabetes. Simmons' (2001) framework for analysing barriers to diabetes care also emphasises the importance of social support. Simmons (2001) also includes personal health beliefs as a potential barrier to utilising care. The findings of this research are consistent with this assertion, for example Pacific Islanders have different ways of understanding health and health care delivery, which in turn shapes individual health beliefs and the utilisation of care.

However, the results generated from this research have raised several other important issues that must be taken into consideration when assessing why people do not utilise diabetes educational services. For example, perceptions of the body, denial and fear, the effects of stigma and the perceptions of health providers were emphasised and can be considered as barriers to utilising diabetes care and educational facilities in Christchurch. These ideas may also be related to individual preferences of diabetes care and educational providers. Diabetes is a serious concern in the Pacific Island community, as diabetes rates are markedly higher in Pacific Islanders than Europeans. Given the severity of impact that diabetes can have on individuals, families and communities it is vital to have a complete understanding of the barriers that influence utilisation of diabetes care and education.

Perhaps a new model for exploring barriers to health care utilisation needs to be developed. I argue however, that the depiction of barriers to care, diagrammatically, displays barriers as being somewhat static and simplistic. It also contradicts the complexity and interrelatedness of the factors influence barriers to utilising care (Anderson et al 1991; Glasgow et al 2001; Zigbor and Songer 2001). Understanding barriers from within local environments would allow for a place-specific, people-centred approach to investigating barriers to using health care services.

People's perceptions and individual and cultural ways of knowing and understanding health must be considered when exploring barriers to care. One way this can be achieved is by utilising in-depth qualitative research strategies, for example interviews and focus groups which allow people to express their feelings in detail, therefore a greater understanding can be gained. However, different cultures have different ways of knowing, understanding, and approaching health and health care. Therefore,

mechanisms for analysing barriers to care must be adaptable to these different ways of knowing. The utilisation of health care is a complex issue with a multiplicity of intervening and interacting factors. Health professionals need to consider the array of factors that influence utilisation and perhaps barriers to care need to be explored at the individual and community levels to gain a greater understanding of the local environment and individual health beliefs.

CHAPTER 8

The Diabetes Societies and Utilisation: A synthesis

8.1 Introduction

Diabetes and diabetes education in New Zealand are complex issues. This chapter draws together the main themes from the results and interprets them through the theoretical and conceptual insights illustrated in Chapters Two to Four. It aims to create a synthesis between the quantitative and qualitative data and readdress the thesis objectives within this context. The objectives of the thesis were to: first, to investigate the role of and perceptions surrounding the diabetes societies in New Zealand and the influence of geographical factors on these perceptions; and second, to provide an in-depth exploration of the extent to which diabetes educational services are utilised in Christchurch. Educational services are utilised but not always by the groups that need them most, for example, Maori and Pacific Islanders. As such the key themes that will be addressed in this chapter relate to the role of the diabetes societies for social support, the influence of rurality, different modes of organisation and deprivation, barriers to utilising educational services and provider preferences.

8.2 The Diabetes Societies and Social Support

It emerged from the questionnaire analysis that the support which members receive from their diabetes society is an integral part of their diabetes education. Thus a key role of the diabetes societies in New Zealand is social support. The emotional support, the friendly environment and the companionship obtained through participation in the diabetes societies is a very important component of diabetes education for members. It is through this social support that members may be able to achieve better diabetes management.

Members of the diabetes societies perceived a primary role of the societies to be sharing information and providing support. The societies, therefore, have a vital role

and offer services that may not be provided in a more clinical environment. The role of the societies is illustrated by one member's response, "we're a more friendly face", and another member commented that their society provided a supportive environment where the "small problems" could be discussed. The geographical concept of place is also important here. The diabetes society is a site where there is an intersection of social relations, collective memories and the construction of meanings along with encapsulating and communicating identities (Kearns and Barnett 1997). Conradson (2003) explores the formation and durability organisational spaces through the employment of Actor Network Theory (ANT). However, ANT does not allow an exploration of the 'daily goings-on' within organisational spaces. It is important to see organisational spaces, like the diabetes societies, as embodied practices, and investigate the immaterial and affective dimensions of such spaces. By incorporating the concept of place, where identities to be constructed, contested and re-negotiated (Johnston et al 2002) an in-depth understanding of organisational spaces can be gained. Place is more than space as holds human intentions and values (Gesler 1991; Gesler 1992; Kearns and Moon 2002). Duncan et al (1993) argue that places matter because they are the context within which health related behaviour occurs. Therefore it is vital to increase our understanding of place in relation to health and health behaviours.

It emerged from this research that the presence of a diabetes society in many communities is more than an educational facility. The society held significant meanings and collective experiences, for members and is a place for social interaction and support. By exploring members' perceptions and experiences of the diabetes society insight into how it influences health can be gained. Kearns (1991) asserts that the presence of health services in a community can provide a rich texture of human experience, communication, interaction and support. It may strengthen people's belonging to, and perception of, place and reinforce the social fabric.

However, not all people with diabetes receive social support through the diabetes societies. The diabetes societies are one illustration of a social network, this relates to Conradson's (2003) research on organisational spaces using ANT. This frames organisations as being embedded in the resources and other material entities through which agency is constructed, within these networks, however, there are variations. These variations will be discussed further in the following section. For Pacific

Islanders the importance of the family, as a carer at home, was strongly emphasised. In this case the family could be viewed as a social network. The family environment could also represent a symbolic place of healing for Pacific Islanders. The importance of the family demonstrates the importance of cultural values to health and why cultural perspectives matter (Gesler 1991).

However, social networks can take many forms. Patricia, a New Zealand European, from the medical centre in Christchurch, indicated that the “old peoples place” around the corner was an important place for her and her friends. This place then becomes a platform for social interaction, sharing information and shared meanings. These interactions are vital as people realised that many people had diabetes and they did not need to feel alone or ‘abnormal’. Participating in physical activity as part of a group illustrates that social support, interaction and networks can provide an environment for health promoting behaviours.

There is a wealth of literature on the importance of social networks for health (Rose 2000; Greiner et al 2004; Kritsotakis and Gamarnikow 2004; Locher et al 2004; Shortt 2004; Pollan and von dem Knesebeck 2004). Therefore, social capital is a relevant and important concept in the context of this research. Social capital can affect health by increasing access to health services and amenities and by enhancing psychosocial processes through the provision of emotional support within trusting environments. The findings of this research are consistent with the idea that social networks are important for health. Putnam (2000, p19) asserts that social capital involves cooperation and trust at the level of societies and that the core idea of social capital is that “social networks have value”. Kritsotakis and Gamarnikow (2004; Locher et al 2004) assert that one of the defining characteristics of social capital is participation in voluntary communal organisations. The findings of this research agree with Kearns’ (1991) study that examined the contribution of health services to the experience of place in the Hokianga region of New Zealand. Kearns asserts that a humanistic understanding of place in health care delivery is important. It was found that “smaller community-based facilities contribute to the broader health of the communities by acting as gathering places and arenas of information exchange” (Kearns 1991, p529). Like the diabetes societies in New Zealand, Kearns (1991, p530) found that health services in the Hokianga highlighted the “rich texture of human experience and interaction that can be propagated by the presence of human services”.

A lack of social interaction and social capital could be classed as social deprivation (Gatrell 2002). For example, through the diabetes societies members may obtain information about how to access other diabetes-related health providers, such as exercise professionals. Participating in the diabetes society may enable members to talk about their approaches to exercise in a comfortable manner along with receiving support and encouragement. Therefore social networks can create a sense of belonging and trust within a supportive environment. The idea that one's social environment and social interactions influence health relates to the social model of health outlined in Chapter Three.

Through the qualitative and quantitative analysis, these findings suggest social interaction at an individual level may also influence health and health outcomes and help people with diabetes to achieve better management. Good social support and social networks have been shown to decrease mortality and provide positive health outcomes (Kritsotakis and Gamarnikow 2004; Locher et al 2004). Participation and interaction with the society may help members to achieve better diabetes management. At the individual level, members of organisations are able to secure benefits due to the enduring nature of the relationships that have formed. Therefore, engaging in society activities may help to promote health behaviours and discourage unhealthy ones (Locher et al 2004). For example, the diabetes society may provide a platform from which diet and exercise can be better managed.

Diabetes society membership predominantly consisted of females over the age of 50. Furthermore, more females responded to requests for participants when conducting qualitative fieldwork. Although this may be related to the older age of onset of type 2 diabetes, it is still important. Greater involvement of older adults in the diabetes society may help to achieve better health outcomes among this group. Brown (1988) found a statistically significant relationship between patients who attended diabetes educational services at the Diabetes Centre in Christchurch and hospital admission. There was a two-fold difference in the proportion of individuals admitted to hospital between attenders and non-attenders of the educational services (Brown 1988). Locher et al (2004) suggests that older adults with greater social networks and more social support systems experience better health. Furthermore, as a person's age increases, the need for social support also increases. This highlights the vital role that

the diabetes society plays for older members and how the diabetes society, as a place, may take on different meanings for various age groups.

The under-representation of males in the diabetes society membership may suggest that males feel less comfortable talking about their diabetes. This under-representation may relate to the issue of a stigma being associated with diabetes and the unwillingness of people to express personal information (Lichtenstein 2003; Prior et al 2003). The effects of stigma will be addressed further in a following section. The idea of a stigma could be constructed and experienced differently in males and females, thus influencing interaction and participation with social networks like the diabetes societies. The difference in participation may result in gender differences in diabetes related knowledge which may have important implications for health care delivery and practice. It postulated The Royal New Zealand College of General Practitioners (2002) that men visit their general practitioner less often than women. This finding is consistent with Melia et al (2000), who found that attendance at a melanoma screening clinic in the United Kingdom is lower for men. This difference may also have important implications for diabetes care and management, especially given the importance of the general practitioner as a diabetes care and educational provider.

Furthermore, Putnam (2000) asserts that informal community involvement and social connections are more frequent among women. Daniulaityte (2004) also concluded that there is a much higher level of cultural sharing among women than men. Women tend to have a greater direct knowledge, of and relationship with, their illness status. Therefore, women may reach a greater level of self-actualisation which in turn may influence better health behaviour.

Male participation in health promotion and care needs to be encouraged as it can have beneficial outcomes for society. Gender related inequalities reflected by variations of diabetes-related knowledge have important implications for diabetes care and education. It has been suggested that to achieve gender equality in health there needs to be a reconstruction of ideas of masculinity (Daniulaityte 2004). For example, the desire for some males to be seen as 'hard' may prevent them from admitting to a perceived weakness and seeking advice from a doctor (Doyal 2000). In New Zealand

the stereotypical notion of the 'kiwi bloke' (Law et al 1999, p217) is pervasive and reinforced through pop culture.

A stereotypical 'kiwi bloke' is at home drinking beer in rugged rural environments. Asking for help or admitting to a problem would not be considered part of the hard kiwi bloke culture, as 'she'll [sic] be right mate' epitomises stereotypical kiwi masculinity (Law et al 1999). Law et al (1999) also argue that rural environments, particularly the West Coast of the South Island epitomise traditional kiwi masculinity. It was raised that, in rural areas, access to health care for some males is difficult. There may be a barrier for rural males in terms of utilising health care. This notion relates to Law et al's (1999) assertion that rural environments embody the stereotypical kiwi bloke masculinity. Rural males may therefore pride themselves and aspire to become an iconic kiwi bloke. Admitting to having a problem may not fit this ideal, and as such health problems may go unchecked. In relation to diabetes, particularly type 2, this is important given the insidious onset and the severity of complications if left unchecked

The pervasiveness of the idea of 'kiwi bloke' and associated characteristics may influence some men's utilisation of health care. Therefore, male participation in health promotion in various parts of New Zealand must be understood to ensure that there is equality in health care utilisation, this is important in relation to diabetes given the risk factors for men, such as increasing abdominal adiposity with age, and the severity of complications that can result. Social networks also vary regionally and are defined by the social and cultural order within each place (Dyck et al 2001; Marmot 2004). Therefore, the diabetes societies take on different meanings in different places and provide members with diverse experiences.

8.3 The Importance of Geography: The Influence of Rurality, Different Models of Organisation and Deprivation for Society Membership

Moon (1993) argues that places and the characteristics of places matter because they are the context in which health related behaviour occurs. Chapter Three outlines how a geographical approach to health and health care can offer many valuable contributions. An insight into how place affects health can be obtained by exploring the influence of the local environment and features of the material infrastructure

(Macintyre et al 2002; Curtis et al 2004). Three important characteristics of place have emerged from this research. These themes are: the influence of rurality, modes of health care organisation, and deprivation. The following section discusses the role of the diabetes society and members' perceptions of their diabetes societies will be discussed in light of these characteristics.

8.3.1 The Influence of Rurality

It emerged that members of rural societies are more involved with their diabetes society, and perceived it to be more effective in addressing the growth of diabetes than urban society members. These differences may be related to the different nature of the diabetes society within each area. However, it is also important to consider the influence of geographical factors, such as the influence of rural and urban environments for example, and how these different contexts shape access to health care. Furthermore, rural and urban environments cannot be viewed in isolation, therefore the role of different socio-economic, political, cultural and economic structures at the individual and community level are important when considering differences between the diabetes societies in various areas.

Health and health services in rural New Zealand are an important and often highly politicised issue. Rural areas often face difficulties attracting and retaining health professionals, specifically general practitioners (Gordon et al 1992; Hewitt 1992; Burton 1999; Creech 1999; London 2002). In New Zealand, rural diabetes societies play a vital role in diabetes care and education. Although general practitioners are the preferred diabetes educational provider by the society members, there is a strong reliance by rural society members on the diabetes society as an educational provider. The society, although not strongly preferred, is the provider that more rural members actually received their education from. It is also the most utilised in terms of advice and as a source of information. These results may reflect a shortage of primary and secondary care providers in rural areas, thus the nature of service provision differs between rural and urban environments enabling the diabetes societies to take on various roles. It could also be suggested that barriers in accessing other health providers are present to a greater extent for rural society members, for example in terms of increasing costs or dissatisfaction with other providers.

Community networks are a vital part of life in rural New Zealand (Scott et al 1997). The diabetes societies in New Zealand could be thought of as a community network. A lot of health care in rural communities is provided by community networks and voluntary organisations (Burton 1999; Farry 2002). The higher rate of participation and involvement with the society by rural society members fits with Greiner et al's (2004) assertion that individuals from rural areas have the highest rates of community involvement, especially in health-related organisations. Barnett and Barnett (2003) argue that during the 1990s, in response to the threat of rural hospital closure, there was a re-emergence of voluntarism in the form of community hospital trusts in southern New Zealand. It is argued that the return to local voluntary involvement in these rural areas of New Zealand is reminiscent of Wolch's (1990) conceptualisation of the 'shadow state'. Barnett and Barnett (2003) state that collective human action, community leadership and capability, and the political and economic context, such as the introduction of market-led reforms, influence the establishment of community health trusts. Therefore, both structure and agency are important in shaping health care delivery and subsequently individual and community health. It could also be argued that the formation of community health trusts within rural communities could provide a sense of empowerment which may also result in positive health outcomes (Anderson et al 1991). Structure and agency are also important for the development of the diabetes societies. For example, the role and operation of the diabetes society is shaped by the structure of the regional health care system, however this role could not be fulfilled without collective human action and the involvement of local health professionals.

Marmot (2004) asserts that social capital is one way in which place can affect health. The integral role of the diabetes society for diabetes care and education may also enable it to take on a specific meaning in rural areas and contribute to members' understandings of place. This meaning is also related to the concept of social capital that was discussed in an earlier section. The diabetes societies and the nature of social capital may vary between rural and urban areas. Therefore, the greater involvement and interaction with the society by rural members may suggest that there is a stronger social network, influencing feelings of greater support by rural members. This involvement could result in more health promoting behaviour.

The way health care is provided is likely, albeit subtly, to influence the character of a place (Kearns 1991). The way that health services are provided and valued within a community, for example through the diabetes society, actively contributes to the vitality of that community. Furthermore, a community may feel increasingly positive about their place and increasing the level of interaction and information exchange within the community. Therefore, features of the local environment play a role in influencing the health of individuals (Sooman and Macintyre 1995). For example, the smaller size of many rural societies may influence the nature of interaction and friendships that result. Olson (1971) argues that there is a greater coherence and effectiveness within small groups. Olson (1971, p53) asserts that collective “action taking tends to occur more frequently and is more effective in smaller groups”. These findings could also illustrate that the diabetes society, a place where social interaction, support and education occurs, takes on different meanings in rural and urban communities. This may also be the case between where the regional health care system is organised differently, for example, decentralised networks having more community outreach fostering interaction and participation.

8.3.2 Models of Organisation

It was found that a more decentralised model of health care organisation, in comparison to a more centralised model, led to a greater level of involvement and interaction with the diabetes society. Members of the society within a more decentralised society also perceived their society to be more effective in dealing with the growth of diabetes in comparison to members of the society within a more centralised network. These results illustrate that the underlying institutional, economic and political structure and organisation of health care delivery can influence human action and health seeking behaviour (Gelser 1991).

Hurley et al (1995) argue that centrally organised services tend to be more supply-oriented and bureaucratic with the delivery of uniform services. Centrally organised services also tend to involve a model of provision similar to central place theory, a central tenet of this being that consumers can move unimpeded through an even distribution of health care services (Jones and Moon 1987; Johnston et al 2002). However, the findings from this research demonstrate that access and movement is

not always unimpeded. The differences in participation and involvement that emerged between Society A (centralised network) and Society B (decentralised network) may illustrate that barriers to access and utilisation exist for some people, thus movement is not unimpeded.

A decentralised model of health care delivery addresses the hierarchical arrangements of a more centralised model. It involves the dispersal of service providers and maximises opportunities for community involvement. A decentralised model attempts to match services to local needs. It also aims to utilise local knowledge, encourage collaboration and attempts to make services more accessible and user friendly for consumers (Curtis and Taket 1996; Pinch 1997).

The greater participation and involvement from society members within a decentralised network is consistent with Hurley et al's findings (1995). Hurley et al (1995) assert that decentralisation and increasingly decentralised systems give greater authority to local decision making by giving the public a greater voice in the decision making process, in turn leading to greater community involvement. Decentralisation also allows improvements in technical and allocative efficiency within health care systems. Hurley et al (1995) conclude that decentralised structures have a greater potential for efficiency in the organisation and delivery of health care services. The increased level of community involvement may lead to a greater sense of empowerment, a key concept for health promotion, which was discussed in Chapter Three.

A decentralised structure with increased community interaction may encourage greater membership of the local diabetes society. Ultimately, this could lead to better health outcomes. However, it is also important to keep people with diabetes out of hospital. Brown (1988) illustrates a significant relationship between diabetes-related hospitalisation and the organisation of health care service provision and the availability of resources. Therefore, the nature of institutions and the social, economic and political structures which health care is situated are therefore important for health outcomes and health behaviour. Different models of organisation may also result in different ideologies which could influence the operation of organisations, for example the diabetes society, within given areas. Therefore, the diabetes societies in New Zealand cannot be isolated from the structural context in which they operate.

8.3.3 Deprivation

The deprivation profiles of the diabetes societies that were presented in Chapter Six revealed interesting contrasts. It was found, overall, that there are fewer diabetes society members in areas with high and low deprivation. In the urban societies there are lower membership levels in areas with high deprivation. Also there are fewer members of Society A (within a centralised network) in highly deprived areas. Thus, it is important to consider how deprivation may influence diabetes society membership.

The lower membership levels in higher deprivation deciles that are shown in these results may indicate that highly deprived people in these areas are 'hard-to-reach'. There may also be an inequitable distribution of, and access to, diabetes care and educational services in more deprived communities within these areas. This finding is consistent with Melia et al (2000) who found that attendance at a melanoma screening clinic in the United Kingdom was lower for people from more deprived areas. Access to diabetes services is a critical component of diabetes care and education. Zigbor and Songer (2001) argue that people of lower socioeconomic status are less likely to receive specialist care and to use preventative health services. Lower socioeconomic status has been associated with lower levels of diabetes knowledge. This lower level of knowledge may influence health care utilisation (Zigbor and Songer 2001). It was also found that patients with lower levels of income were more likely to forgo care (Zigbor and Songer 2001). There may also be barriers to accessing early intervention services, for example, transportation and cost. Forgoing care may be related to preventative health care not being a priority for lower income groups, especially in the case of type 2 diabetes, as there is an insidious onset. Therefore, socioeconomic status is an important risk factor for non-utilisation of diabetes care and educational services.

The concern with health and deprivation is not new (Gatrell 2002). It is argued by several authors that socioeconomic status affects health and access to health services (Dahlgren and Whitehead 1992; Higgs and White 1997; Evans et al 2000; Gatrell 2002; Barnett and Lauer 2003; Agardh et al 2004; Marmot 2004). Drever and Whitehead (1995 cited in Gatrell 2002, p124) have shown a clear link between deprivation and all-cause mortality. Poverty, unemployment, low educational

attainment, inadequate housing and sparse food supplies, for example, are all more common in disadvantaged neighbourhoods and groups and influence health and health behaviours. People with lower incomes have limited dietary choices and households may have poor access to a range of nutritional foods (Gatrell 2002). In relation to diabetes this is important as the increased consumption of saturated fats leading to overweight or obesity is a risk factor for diabetes. Unemployment can also restrict household choices and may result in preventive health strategies not being a priority. Evans et al (2000) also assert that deprivation is associated with higher rates of diabetes, as there are more obese people with type 2 diabetes in highly deprived areas. Given the insidious nature of type 2 diabetes, higher rates in more deprived areas and the severity of complications that can result, the influence of deprivation as a barrier to access and utilisation of diabetes care and educational services must be taken into consideration.

Karrer et al (2000) found that lower levels of educational attainment were also independently associated with non-adherence to recommendations for blood glucose self-monitoring. This non-adherence may be related to lower levels of diabetes-related knowledge. A study conducted by Simmons et al (1994) revealed ethnic differences in diabetes-related knowledge in South Auckland, a more deprived area of the city. It was found that Pacific Islanders knew the least and Europeans knew the most. Pacific Island patients were also the least likely to have received diabetes education. These findings are significant in the context of this research because Maori and Pacific Islanders were under-represented in the diabetes society membership. Such findings are also relevant in the New Zealand context given that Maori and Pacific Islanders are at a higher risk of developing type 2 diabetes and have higher rates of deprivation (MoH 1999). Diabetes-related knowledge was positively associated with having received diabetes education upon diagnosis (Simmons et al 1994; Simmons et al 1996). Therefore it is important to understand the complex interplay between cultural and economic factors in relation to health care utilisation.

8.4 What Stops You: Barriers to Diabetes Education in Christchurch

Many barriers exist in relation to diabetes care and education in New Zealand and a wealth of literature surrounds this issue (Anderson et al 1991; Simmons et al 1999;

Simmons 2001; Zigbor and Songer 2001; Glasgow et al 2001; Zgibor and Simmons 2002). It is important to consider how the specificities of culture and cultural environments interact with health and health care and may result in barriers to utilising health services (Dyck and Kearns 1995; Lasch 2000). There are various ways to classify barriers, however, Glasgow and others (2001) separate barriers into external and internal. External barriers may be in relation to physical access to providers, transportation, availability of health provider and barriers based around the health system. Internal barriers are more patient-based, for example, health beliefs, socio-economic status, cost and satisfaction with providers. Several themes emerged from this qualitative research which can be related to barriers to seeking and accessing diabetes care and education. For example, barriers in relation to issues of gender, the effects of stigma, the denial of having diabetes and conceptualisations of fear recurred throughout this research.

8.4.1 Gender and the Body

Different perceptions of the body, across cultures or individuals, may influence health seeking behaviour and the way health care is perceived. In every society cultural and moral values shape health and health beliefs (Anderson et al 1991; Lorber 1997). Culture is a two-part concept. The first part is the observable realm of events and ways of life within communities. The second part relates to the organised system of beliefs and knowledges whereby people structure their experiences, attitudes and behaviours (Dew and Davis 2005). Therefore, 'culture' underpins the way of life for Pacific Islanders, and has vital implications for health beliefs and subsequently the management of diabetes and diabetes education (Brewis et al 1996; Pawa 2000; Gesler and Kearns 2002). Differences in the way bodies were constructed and experienced emerged during this research. Pacific Island women felt uncomfortable and vulnerable at having to expose their bodies in front of their doctor.

The system of beliefs held by an individual in relation to their body may begin with the physiological but it also contains the cultural (Macdonald 1999). Macdonald demonstrated that biomedical understandings and those of women about their own bodies can differ markedly. The findings of this research are consistent with Macdonald's finding that gendered cultural ideas and practices of bodily shame and

modesty may limit women's utilisation of medical services. In the context of this research, female bodies are constructed as being very private. Males, on the other hand, did not express this view. These feelings may result in feelings of fear and anxiety and appeared to be an important barrier to seeking health care. Conceptualisations of the body also relate to differences in individual and cultural health beliefs and ways of knowing and understanding health and the body (Matthews 1995; Longhurst 1997). Furthermore, it could also be argued that such conceptualisations of the body are not just limited to Pacific Island women.

Patterns of behaviour and values may therefore be promoted and curtailed by cultural norms of behaviour for each gender. In a sense, bodies can then become part of the wider social milieu. Taking "bodies in context" (Moss and Dyck 2003, p52) as embodied within social and cultural relations is important for understanding diabetes health related behaviours. Therefore the way bodies are thought about and experienced may influence health behaviour. Culture and gender also cannot be separated from health and health behaviour. In light of different conceptualisations of the body it is necessary to rethink the efficacy of advertising and research programmes that begin from implicit biomedical assumptions (Macdonald 1999).

Gender has been identified as a source of variation in medical encounters and is an important social category in relation to diabetes (Street 2002; Daniulaityte 2004). Social practices construct and produce social bodies, and gender can influence interactions with health professionals (Lupton 1995; Lorber 1997). Grosz (1990; 1994) also argues that women's bodies are sites inscribed by social expectations in terms of health and body-related behaviour. In the case of Pacific Island women this has important implications for health behaviour. As these findings demonstrate Pacific Island women's bodies are constructed as private. Such conceptualisations may influence health seeking behaviour.

Furthermore, religion plays an important role in the lives of many Pacific Islanders (Saau 1996). The Christian church is a central means of providing embodiment for Pacific Islanders and Pacific Island knowledges (Tiatia 1998). The church is also viewed as an institution that seeks to reinforce and maintain cultural values. Therefore the church may be an important way through which cultural values, for example modesty, surrounding female bodies are maintained. Feelings of discomfort

with male doctors, expressed by female Pacific Islanders relates to Saau (1996) assertion that that Samoan females feel more comfortable with female rather than male doctors. This idea may also illustrate that some people, and in the case of Pacific Islanders especially women, may feel uncomfortable with males in positions of power and who are considered to be 'experts'.

The aforementioned comments relate to Foucault's ideas of medical knowledge (Foucault 1967; Lupton 1995). Power relationships are intrinsic in the medical system, for example providers dominate patients. Hierarchies also exist among medical systems, namely biomedicine and alternative systems (Haraway 1991; Gesler and Kearns 2002; Gillespie 2002; Broom and Whittaker 2004). Foucault argues that the development of medical knowledge relates to the development of power and knowledge resulting in social control (Foucault 1967; Lupton 1995; Davis and Dew 1999). Medical professionals have an integral role in this process. The use of knowledge can be used to gain or maintain positions of power and control over other people (Macdonald 1999; Kearns and Barnett 1999). Therefore, as an expression of knowledge, language is also power. Thus "knowledge = power" (Gesler and Kearns 2002, p84).

In the context of this research Foucault's ideas are relevant as people from the medical centre in Christchurch indicated feeling more comfortable with their nurse than their doctor. In this instance the doctor may be in a position of greater power, the doctor may also use language differently which has implications for the dissemination of knowledge and therefore power.

Language does not exist in a vacuum, and certain words or phrases may be understood differently by different cultures (Macdonald 1999). There is a voluminous literature on language and communication difficulties and their influence on health care delivery, Timmins (2002) provides a comprehensive discussion. Experts also play a vital role in the modern system of power and knowledge creation (Petersen and Lupton 1996). This also relates to ideas of empowerment, whereby people become pro-active with their diabetes, this will be addressed further in a following section.

Cultural knowledges and values can influence ideas about the body and health beliefs. Bodily inscriptions are those material manifestations of social, cultural, religious and

political ideas and notions about the body. Within this approach bodies are already coded and women's bodies are constructed differently to males. However, viewing the body as a mere surface upon which cultural values and ideas are layered reduces the body to a passive vessel which is void of any interactive capacity (Moss and Dyck 2003).

8.4.2 The Effects of Stigma

The presence of a stigma being associated with diabetes recurred throughout this research. Participants did not feel comfortable talking about having diabetes. One participant noted that "no one wants to go around saying I've got diabetes". Lichtenstein (2003) found that the presence of a stigma can act as a barrier to accessing and utilising treatment. This may be the case not only in Christchurch but other places in New Zealand.

The unwillingness of, especially Pacific Island, participants to talk about their diabetes in particular environments and with certain people may also relate to the presence of a stigma. This discomfort is expressed by Karen as she found it difficult to talk to Mr Smith, as mentioned above. This finding is consistent with Prior et al's (2003) argument that the presence of a stigma is related to an unwillingness to disclose emotional or personal problems. Tak-Ying Shiu et al (2003) also found that social stigma was a barrier to diabetes self-management. The presence of a stigma may therefore influence people's diabetes educational preferences. This will be addressed with more detail in a following section.

Health and well being is important for people's identities. As Gesler and Kearns (2002) assert, an important aspect of identity formation is how others dictate what should be done to one's body. This ultimately links with health and ill health because health advice is often prescribed to people, in relation to diabetes people may be told to lose weight, increase physical activity or inject insulin. These health behaviours may then construct and re-construct identities around such health-related behaviours. People may not want to be identified as having an 'illness' or labelled as being 'sick'. This in itself may create a stigma and could act as a barrier. In line with cultural beliefs and values about particular conditions, 'labelled persons' are more likely to be

associated with undesirable characteristics, which may create a barrier to seeking advice and talking with other people (Schulze and Angermeyer 2003, p300).

Stigma may also be experienced differently among different cultural or social groups. For example, the lower number of males who belonged to the diabetes society may reflect that the stigma is experienced differently between males and females. In addition, it was expressed by several rural society presidents that due to the smaller size of their town where 'everybody knows everybody' people did not want others knowing they had diabetes. Concern was raised over employability and being questioned over eating cakes. The presence of a stigma may reflect the preference towards more individually based providers, such as GPs and practice nurses.

8.4.3 Fear of the Truth and Things Foreign

Fear of the truth and of foreign things appeared to be an important barrier to utilising care, especially for Pacific Islanders. Medical clinics and equipment are constructed as foreign, and instil fear and anxiety within people. Even diabetes itself was framed as a 'foreign disease' and a 'foreign illness'. Spaces are not neutral and construct particular meanings for people (Gesler and Kearns 2002). This relates to conceptualisations of fear expressed by Pacific Islanders. The conceptualisations of fear that were articulated were generally associated with a particular place, namely the clinical environment at the hospital or specialist centre.

Gesler and Kearns' (2002) argue that individual perceptions of particular places and landscapes, along with the meanings that are attributed to them, are important ways of understanding and interpreting places and environments. In a hospital environment many concrete objects that patients encounter may have symbolic meaning. For example, the high-tech equipment may frighten people (Kearns and Gesler 1998; Gesler and Kearns 2002). For Pacific Islanders this is important as such equipment is also perceived as being 'foreign' and not the 'norm' within their culture and society, and something that should be feared. Therefore, in this case, fear may act as a barrier to seeking health care and it is an example of how a particular place impacts on health behaviour. Furthermore, the construction of diabetes as 'foreign' provides insight into

variations between cultures about the causes of diabetes. Therefore, different health beliefs may influence health behaviour.

Gillespie (2002) also notes that even architecture, as a means of ordering space, can have significant implications for cultural practices associated with health behaviour. This notion is relevant as some Pacific Islanders expressed feelings of anxiety from high-tech equipment and the 'clinical look', which could include the buildings. As such the architecture of health spaces can impact upon social relations. It is also suggested that through the structures and spatial arrangements hospital architecture is embedded within dominant cultural values. Inequalities between doctors, patients and medical authority can also become embedded within the spatial design. Pacific Islanders may feel alienated in this environment as their ways of knowing and understanding health and health care may be subservient. Furthermore, this type of architecture may not be normalised within Pacific Island culture. The foreign nature of the architecture and environment may manifest feelings of fear which could influence health behaviour. Therefore, "we shape our buildings, and afterwards our buildings shape us" (Churchill 1943 cited in Gillespie 2002, p211).

Glasgow et al (2001) assert that health-related advice and recommendations are sometimes not consistent with cultural values and health beliefs. In turn this may subvert individual self-care and self-management. It emerged that many elderly Pacific Islanders cannot speak English well and have difficulties responding to questions asked by health professionals. As the risk of developing type 2 diabetes increases with age, coupled with Pacific Islanders having higher rates than Europeans, this is a very important issue. Different ways of communicating and language barriers often exist between health professionals and Pacific Islanders. The way issues are approached and addressed in different cultures may also present a barrier to seeking health care. The social relationships, interactions and conversations within places are also important for health related behaviour and can create landscapes that can help or harm (Gesler and Kearns 2002). The inability to communicate may manifest feelings of fear and as such may act as a barrier for Pacific Islanders.

It emerged that Pacific Islanders tended not to ask straight away "how is the diabetes?" The specific issue would be talked around before any direct questions would be asked. A sense of trust and a rapport needs to be established between

patient and provider to enable issues to be talked about openly. The perception of a lack of trust and rapport with health providers, expressed by Pacific Islanders, related to feelings of not being listened to and understood. Feelings of a lack of trust and rapport were heightened by the frequent use of a technical and medicalised discourse during consultations. Thus language and place are related and have a reciprocal relationship. Places, for example, doctors consulting rooms may give rise to certain conversations and have certain expectations (Gesler and Kearns 2002). Trust is also a form of social capital (Franzini and Fernandez-Esquer 2004). Franzini and Fernandez-Esquer (2004) state that a sense of trust and being trusted can have positive influences on people's health and health outcomes. The perceived lack of trust between patient and provider may be acting as a barrier to accessing and seeking health care for Pacific Islanders.

8.4.4 Denial

The denial of diabetes and its seriousness recurred throughout this research and appeared to be an important barrier in the utilisation of care. It was also expressed that people tend to build a fence around them which may act as a barrier to accepting and receiving information. It emerged that it was not until people are admitted to hospital that they realised they had diabetes. Denial generally denotes the refusal to acknowledge something, a statement, idea, condition, or in this case diabetes, it can be conscious or unconscious (Levine et al 1994; Anderson et al 2002). Denial also acts as a psychological defence and coping mechanism enabling people to disavow the knowledge or meaning of event, a stressor, and the feelings that are evoked. It is a nursing diagnosis accepted by the Eighth National Conference on the Classification of Nursing Diagnosis. A defining characteristic of denial is that people delay or refuse to seek medical attention. The person does not perceive the personal relevance of the symptoms or danger. The individual generally does not admit fear in relation to the health problem and is often unable to acknowledge the impact of the problem on his or her life (Anderson et al 2002).

These characteristics of denial also emerged through the qualitative research. Participants expressed not feeling "bad enough" and not perceiving themselves at risk of type 2 diabetes. Patricia commented that her diabetes was discovered through a

routine blood test, and when the results came back she “definitely had it then”. It is important to recognise denial and refusal to seek medical treatment, especially given the insidious nature of type 2 diabetes and the severity of complications that can result if left untreated. The notion of denial gives prominence to the need for increased and ongoing education of the community about diabetes, how to recognise the symptoms and understand the complications that can result.

The idea of denial may also relate to people’s knowledge, understandings and awareness of diabetes. Denial may also be related to conceptualisations of risk and whether people think they are at risk of developing diabetes. Patricia and Sarah commented that they did not even think they would get diabetes, Patricia stated that as she had got to this age she would not develop diabetes. This idea is consistent with the assertion of Anderson et al (2002) that relates to denial being associated with individual perceptions of the personal relevance of the symptoms and risks associated with a health problem. For example if a person does not perceive themselves to be at risk from the development of type 2 diabetes this may influence the presence of denial as coping mechanism if diagnosis occurs. There is an abundance of health promotion material presented to inform people of the ‘risky’ aspects of our lifestyles and how to implement change. This material seeks to influence behaviour leading to the avoidance of illness. However, given that many participants in this research discussed issues of denial the appropriateness of health messages in relation to cultural beliefs must be addressed (Petersen and Lupton 1996). It is important to gain insight into people’s perceptions and knowledge of the risk factors associated with diabetes. Understanding these, may have implications for the nature of information that is disseminated at the level of public health.

Simmons (2001) pertains that denial relates to differing perceptions of the importance and priority given to health. Therefore, it is vital to understand and respect different cultural values and ways of knowing and learning to help promote health and achieve positive health outcomes, especially when Pacific Islanders are at an increased risk of developing type 2 diabetes. This also brings to the fore the issue of empowerment, which will be discussed in a following section.

8.5 Diabetes Educational Providers

It emerged throughout this research that there is a preference towards more individually based educational providers, such as GPs and practice nurses. Members of the diabetes societies preferred individually based providers to a greater extent than group environments, namely the diabetes societies. Members of the medical centre in Christchurch expressed feeling more comfortable with their practice nurse rather than being involved in a group situation. The tendency to prefer individually based providers may be related to the presence of a stigma. People may feel uncomfortable talking about their diabetes in a group situation, especially if they are experiencing denial in relation to their diagnosis.

However, it was expressed by Pacific Islanders during the focus group that the family and the family environment are important for diabetes education. The importance of the family and extended family structure is also illustrated by Tiatia (1998) and The Royal New Zealand College of General Practitioners (2002). It was expressed that health providers need to be culturally sensitive to the needs of Pacific Islanders and that only Pacific Islanders know Pacific Islanders. It could be inferred that Pacific Island health providers may be more preferred by Pacific Islanders. However, this preference does not necessarily mean greater levels of utilisation. Therefore the importance of the Pacific Island Health Centre in Christchurch within the network of diabetes care and educational providers must not be overlooked.

The preference for GPs to provide diabetes education highlights the important role of the general practitioner within the network of diabetes care and educational providers. General practice has a pivotal role in the provision of primary health care. It is the first point of contact for people and, in New Zealand, provides access to the health system, for example, diabetes specialists (The Royal New Zealand College of General Practitioners 2002). Through general practice a continuity of care can be achieved, therefore long-term and trusting relationships can be built. This rapport is important for diabetes, especially type 2, as through continued contact the GP may be in a better position to detect the subtleties of an insidious illness. The primary care environment is also important for encouraging patient empowerment. Empowerment is important for diabetes as it can help to foster self care and self monitoring (Hruby et al 2002; Bekic et al 2004). Beaven and Scott (1986) argue that comprehensive diabetes care

can be provided in a primary care environment through primary care. However, community participation in primary care is a contested issue (Neuwelt and Crampton 2005). It is argued that there is limited research on the benefits of community involvement with health and that community participation is not a simply an establishment issue, but involves an on-going proactive partnership between health providers, iwi and 'communities' (Neuwelt and Crampton 2005).

The increasing move towards primary care is also illustrated in the literature, and is outlined with more detail in Chapter Three (Crawley 1999; Hughes 1999; Gatrell 2002, p140; IDF 2003a; Ministry of Health 2003a; PCD Europe 2004). The move towards an increasing reliance by patients on primary care providers may have implications for general practitioners and practice nurses within medical centres and Primary Health Organisations (Foote 2000). It may affect their work load and increase the need to have specialist knowledge, for example, pertaining to diabetes. This is not to say the role of the diabetes society would change but it may influence their operation within a more primary care focused health system (Foote 2000). The move towards primary care may also have different implications in different areas, for example rural and urban areas.

The increasing tendency and preference towards GPs, indicated by diabetes society members and which is highlighted in the relevant literature may have significant implications for rural areas. Rural general practice in New Zealand is facing increasing difficulties in recruiting and retaining GPs. As such the current workforce is placed under significant stress. This stress is exacerbated by the overall shortage of general practitioners in rural areas (London 2002; The Royal New Zealand College of General Practitioners 2002; Brabyn and Barnett 2004). The demand for specialist knowledge in many fields, diversity of skills and greater demands from communities in which they work may also affect the role of practice nurses. As such the diabetes societies play a vital role in rural areas.

It was identified through this research that a significant gap existed between preferences and the level of provision that was received by general practitioners for diabetes education. More members of the diabetes societies preferred their GP as an educational provider than actually received education from this source. Such findings may illustrate that barriers exist in terms of accessing general practitioners. Barriers

may relate to socio-economic status, distance from provider and transportation. As highlighted through this research, and discussed above, barriers may also relate to a stigma being associated to diabetes, denial of having diabetes or fear of the truth and foreign environments. The decreased level of actual provision by GPs, in relation to levels of preference, may also relate to there being a lack of availability of GPs particularly in some remote rural areas in New Zealand (Brabyn and Barnett 2004).

Although not the preferred provider, the diabetes society provided a significant amount of education for members. The diabetes societies therefore fill a gap in service provision and have a vital role in providing education to members. This education may not be received elsewhere, even though other providers, namely general practitioners, are more preferred. This fits with the frequent assertion that the voluntary sector is a key health provider in New Zealand (McDonald 1993; Milligan 1998; Zauks 1998; Milligan 2000; Wilson 2001; Conradson 2002).

The diabetes societies, as voluntary organisations, provide care and education that is cost effective and is responsive to local needs as the societies are embedded within their communities. They also provide a mechanism for democratic participation and are a powerful medium for orchestrating social change, for example the allocation of health resources. As such the societies are also advocates for people with diabetes. Members also identified the encouragement of self care and self monitoring as being an important element of diabetes care. Given the supportive role of the diabetes societies members may feel encouraged and empowered to take control of their diabetes and increase self care and self monitoring. However, an important component of encouraging self care and self monitoring is education.

8.6 The Importance of Education and Empowerment for People with Diabetes

Education is a vital part of diabetes care (D'Eramo-Melkus et al 1992; Glasgow and Osteen 1992; Fox and Kilvert 2003). It is also important for encouraging self care and self monitoring. It emerged that diabetes education is received from various sources and differed in their preferences towards different types of educational providers. Diabetes education does not occur in a vacuum. According to Glasgow and Osteen (1992) social and environmental factors influence the outcome of diabetes

education. Pearce et al (2005) also found that a reduction in the social gradient associated with melanoma incident in New Zealand may reflect the success of public awareness and educational campaigns, such as 'Slip!, Slap!, Slop!'. The influence of social support for diabetes education is also important. Therefore, the social support that members receive from their diabetes society may result in positive diabetes educational outcomes, and the achievement of better diabetes management.

The notion of empowerment recurred throughout this research, especially during the focus group at the Pacific Island Health Centre. The empowerment philosophy is based on the idea that to be healthy people must be able to bring about changes in their personal behaviour, social situations and in the institutions that influence their lives (Anderson et al 1991). This idea also relates to the findings presented in relation to different models of health care. The nature of institutions may influence an individual's health behaviour. A more decentralised structure may encourage greater community participation and membership at organisations like the diabetes society. Community participation and involvement may serve to empower people and communities to make changes to the institutional arrangement and resource allocation in their areas.

However, empowerment cannot be viewed in isolation. Education is crucial for patient empowerment. It was expressed during the focus group that Pacific Islanders know Pacific Islanders. This assertion is consistent with Anderson et al's (1991) idea that health care professionals may know what is best for a patient's diabetes, but that is not the same as knowing what is best for the patient. In the empowerment view the purpose of diabetes education is to prepare patients to make informed decisions about their own diabetes care. Therefore this knowledge will encourage patients to increase self care and awareness about their own values and needs in relation to their diabetes.

The diabetes societies are one way through which empowerment can be achieved given their important role for education, social interaction, social support and social outreach. However, the importance of other providers must not be overlooked. The Pacific Island Health Centre is also a way in which Pacific Islanders can receive culturally appropriate care and education and take control of their diabetes leading to empowerment at the individual and community levels. Participants from the medical centre in Christchurch identified their diabetes nurse as fulfilling an important role for

their diabetes education. Empowered individuals can lead to empowered communities, and education has a vital role in this process.

8.7 Chapter Summary

This chapter has provided a synthesis between the quantitative and qualitative data that were generated throughout this research using the conceptual and theoretical insights discussed in Chapters two to four. Four key themes have been addressed: the role of the diabetes societies for social support; the role of geography: the influence of rurality, different modes of organisation and deprivation, barriers to utilising educational services, the importance of empowerment and education, and provider preferences.

Diabetes education is a vital part of diabetes care. Ongoing and increased education can lead to increased awareness and the prevention of complications. Education can also help to encourage diabetes self care. The importance of social networks, such as the diabetes societies or the family environment, for Pacific Islanders, are important elements within this process and have a key role within the network of diabetes care and educational providers.

Different epistemologies construct and influence cultural and individual health beliefs. These different health beliefs can then influence individual health-related behaviours and can affect the utilisation of health care facilities. Utilisation of health care services is a complex issue, with many interrelated factors affecting individual utilisation. Barriers to health care may arise at the neighbourhood level, place-based for example a deprived area, or at the individual level, for example gender. It is important to understand these differences and the barriers to health care that emerge to achieve better health outcomes. Health care interventions must address the socio-cultural needs of the target population and recognise the importance of the barriers to diabetes education that exist for different groups. The following chapter will present the conclusions from this research and offer a way forward for diabetes education in New Zealand along with future research suggestions.

CHAPTER 9

Preventing the Human Time Bomb:

Research Conclusions

9.1 Introduction

The research presented in this thesis was designed to increase the understanding of diabetes education in New Zealand, from the perspective of the people with diabetes. It has described and interpreted findings from an investigation of diabetes society members and an exploration of the barriers people experience when utilising diabetes educational services in Christchurch. The purpose of this final chapter is to summarise the main findings of the research and discuss the theoretical and policy implications of this research. This will be achieved by presenting a possible way forward for diabetes education in New Zealand in light of the findings that have been generated. Potential future research ideas stemming from this study are also discussed. Finally, a concluding statement will complete this thesis.

9.2 Thesis Aims and Objectives Revisited

The aim of this thesis is to examine the quality and effectiveness of diabetes education and care in New Zealand. It has two broad research objectives: first, to investigate the role of and perceptions surrounding the Diabetes Societies in New Zealand, the influence of geographical factors on these perceptions, and to explore people's experiences within this diabetes educational space. This objective encompasses four key research questions: First, who belongs to the diabetes societies and do any trends emerge within membership? Second, to what extent do members perceive their society as being effective in dealing with increasing rates of diabetes in New Zealand? Third, to what extent are members involved with their diabetes society? Fourth, to what extent do members prefer their diabetes society as an educational provider? The second research objective is to provide an in-depth exploration of the extent to which diabetes educational services are utilised in the city of Christchurch.

9.3 Main Findings

Several important findings emerged from this research in relation to diabetes education in New Zealand. Throughout this thesis it is argued that to understand diabetes education the perceptions of those who receive education must be recognised and understood. An important provider of diabetes education in New Zealand is the diabetes societies. Therefore it was appropriate to investigate members' perceptions of and experiences within this educational space. In addition, it was also necessary to explore the extent to which diabetes educational services are utilised. This research presents several valuable findings in relation to the barriers that people experience when utilising diabetes education in Christchurch. This section briefly summarises the main findings of this research.

The important role of the diabetes societies, within the network of providers and for members, has been demonstrated throughout this research. The six diabetes societies that were investigated played a significant role for members in relation to diabetes support, education, nutritional advice and through the provision of pamphlets, books and brochures. The opportunity for members to be involved with their society is an important component of the diabetes societies. It is argued that social interaction and engagement with community networks and organisations can result in health promoting behaviour (Locher et al 2004; Kritsotakis and Gamarnikow 2004 among others). For society members, participation and involvement within this social network may lead to improved self-care and diabetes management.

We know that the nature and development of voluntary organisations in New Zealand varies (Barnett and Barnett 2003; Barnett and Barnett 2004). Therefore it was necessary to explore how members' perceptions of and experiences within the diabetes societies varied. An analysis of place-based characteristics, for example differences between rural and urban based societies and between societies situated within different models of health care organisation, highlighted these variations. This research demonstrated that, according to these place-based characteristics, members had different perceptions of the effectiveness of their society and various levels of involvement with their local society. Such an investigation has provided an understanding of the geographies of voluntary organisations associated with diabetes

This research has demonstrated the importance of the diabetes societies for diabetes education. However, it was found that educational services, such as the diabetes societies, are underutilised by certain groups of the population, therefore, it was necessary to investigate why. The New Zealand deprivation data tends to imply that the diabetes societies are predominantly a middle class organisation, especially in cities.

It is argued that 'culture' can act as a barrier to utilising health care (Simmons 2001; Street 2002; Daniulaityte 2004). Gesler (1991) also argues that there is limited research exploring barriers to care from patient's point of view. This research has added another dimension to the exploration of 'culture', as a barrier to utilising care, by going in-depth and trying to understand, from the inside, why diabetes educational services are not utilised. Different conceptualisations of the body, and fear of the foreign and fear of the truth appeared to act as barriers, for some Pacific Islanders, to utilising diabetes educational services. The denial of having diabetes or being at risk also acted as a barrier to utilising services and receiving information.

It was also found that there is a stigma associated with diabetes. This stigma appears to be experienced differently by different people, for example males and females. The presence of a stigma may relate to peoples' preference towards individually based providers, namely GPs and practice nurses, a key finding of this research. It is necessary to recognise how stigma can influence peoples' health-related behaviours, particularly in relation to diabetes given the severity of complications that can result and the importance of receiving adequate diabetes education.

9.4 A Way Forward for Diabetes Education: Theoretical and Policy Implications

This thesis has examined the quality and effectiveness of diabetes education in New Zealand by exploring the members' perceptions of and experiences within the diabetes societies. It has explored reasons why educational services, such as the diabetes societies, are under-utilised by analysing the barriers to care. As a result,

several key theoretical and policy implications emerged. In order to improve diabetes educational services these implications need to be addressed

Despite the rise of the voluntary sector in addressing particular health needs the effectiveness of Diabetes New Zealand and the diabetes societies in providing education and awareness of diabetes, at the macro/national scale, needs to be addressed. However, at the micro/local scale the diabetes societies provide a vital role for members. The elevation of the voluntary sector within the network of care may result in a blurring of the fundamental premise on which their organisations were founded (Milligan 2001). The effectiveness of the provision of education and awareness, at the macro level needs to be addressed because of the severity of diabetes and the complications that can result and the necessity of education for effective self-care, diabetes management and for creating awareness.

It is evident that the organisation of the diabetes societies across New Zealand varies. Although only a limited number of societies were investigated in this study, members' perceptions and experiences within the diabetes societies varied immensely, according to different contextual factors. Essentially, this means that the provision of diabetes education and awareness also varies between societies. It is important to understand what influences diabetes educational provision by the voluntary sector as they are an important stakeholder within the network of diabetes educational providers. Such organisational variations need to be explored and understood in order to address the effectiveness of education and awareness that is provided within communities. An understanding of regional variations may also help to improve provision at the macro level as there may be a greater clarity and definition of the role of the diabetes societies.

At the micro/local level this type of voluntary sector intervention appears to be not relevant for all people. This is evident due to the diabetes society membership predominantly consisting of middle class, older aged persons and Europeans. In relation to the effectiveness of educational provision it is necessary to ask why are the diabetes societies predominantly utilised by such groups, and who is under-represented?

To develop effective educational services it is necessary to understand why current services are not utilised. It is important to explore and understand why those who are not represented in society membership do not utilise educational services. Questions, such as, what barriers do people face and how are they experienced, and what is it about 'culture' that acts as a barrier to utilising health care, need to be asked if services are to be improved. A new model, that incorporates different ways of knowing and understanding health and elements of place, may provide an insight into the barriers to care. It may be necessary to analyse barriers from within local environments. I would argue that the classification of barriers into categories, in a sense, displays health and barriers to health care as being somewhat static, whereas barriers to utilising health care are highly complex and fluid. Understanding barriers from within local environments would allow for a place-specific, people-centred approach to investigating barriers to using health care services.

To achieve greater effectiveness in terms of awareness and educational provision at the national level, should Diabetes New Zealand, as a voluntary organisation, attempt to get greater government support, like many other voluntary organisations? The security of funding allows organisations to provide services and meet community needs in a proactive manner, rather than reactively where funding is short-term and insecure. Although there is a guarantee of funding there may also be increased regulation by the state. There may be geographical limitations on the nature of service provision and funds may be increasingly targeted towards specific areas. Funding regulations may mean that voluntary organisations are unable to respond to areas of need, that they identify, without alternative sources of funding (Milligan 2001). Thus by obtaining funding from grants, membership fees and bequests, as is the case with Diabetes New Zealand, a degree of flexibility and uniqueness may be able to be retained; however this may affect the operation and role of Diabetes New Zealand.

At present the provision of diabetes educational services in New Zealand is somewhat fragmented and variations arise within provision by the voluntary sector. I argue that the role of the diabetes societies at the local level needs to be more readily attributed with a higher level of importance within policy frameworks and strategies. It has been shown that the diabetes societies in New Zealand have a key role within the network of diabetes care and educational providers at the local level, and fulfil a

significant role for members. The diabetes societies 'fill a gap' between other services providers, especially in rural communities

Given the extensive local knowledge that the diabetes societies possess, including them in national or regional educational and awareness strategies may be an important way to work within existing resources. I argue that the nature of the diabetes societies and the services they provide are invaluable. The fact that the diabetes societies are community orientated voluntary organisations gives them an insight into and an understanding of local needs, attitudes and values. In turn, the provision of educational and support services is in response to local community needs, and therefore may be more effective in creating awareness and providing education (Milligan and Fyfe 2004).

However, the diabetes societies are not the only educational provider and the question of how much collaboration goes on between key stakeholders in providing diabetes education must be addressed. How can collaboration be increased between the diabetes societies and GPs, for example, especially given the importance of primary care and the preference by members towards individually based providers, namely GPs? Fragmented, episodic care is not appropriate for people with diabetes and stakeholders need to increase interaction and collaboration to provide more effective diabetes education (MoH 1997; Crawley 1999; Melkus et al 2004).

Furthermore, to improve diabetes educational services, nationally and locally, it is important to gain an understanding from the inside, from the point of view of the people who actually receive the education. An insight into peoples' perceptions and experiences with different diabetes educational services may enable strategies to be implemented that better reflect local needs, therefore allowing more effective educational services to be implemented. However, it can often be a long and difficult process to incorporate the ideas of various groups with different ideas and values (Curtis 2004). While this is a valid point, I would argue that incorporating the consumers of education is necessary to understand if current educational services are to be improved. Such an understanding may also allow for gaps in provision to be identified and subsequently address which would help to increase the effectiveness of services.

9.5 Suggestions for Future Research

This research presents numerous findings relating to diabetes education in New Zealand. However, several key areas warranting further exploration were also identified. Exploration into these aspects would help to achieve more effective diabetes education in New Zealand. This section will outline these areas.

Health, health behaviours and the provision of health care are influenced by the nature and structure of institutions. An understanding of the role of other contextual effects, for example deprivation, degree of urbanisation, within local environments is also important. To assess the influence that institutional organisations have on diabetes-related health a detailed analysis of different models of health care delivery needs to be undertaken. This exploration would provide insight into the effectiveness of different models of health care delivery, which is important in relation to implementing new ideas and programmes. The employment of both quantitative and qualitative research techniques would be valuable as different dimensions of the issue could be elucidated.

The establishment of Local Diabetes Teams across New Zealand attempted to increase collaboration between various stakeholders. It is necessary to investigate the extent to which this collaboration occurs, what factors influence and how interaction varies between the different diabetes teams. Such an investigation may identify gaps in service provision in particular areas and help to address the fragmented nature of diabetes educational provision. Qualitative and quantitative research techniques may be valuable and an approach similar to that of Barnett and Barnett (2003), in their investigation of rural health trusts (referred to in Chapter Three), provides a useful framework for such an analysis.

Recently there has been a re-emergence of institutional geographies (Philo and Parr 2000). Del Casino et al (2000) offer three methodological frameworks, situated within human geography, for analysing the geography of institutions: spatial science, critical realism, and post-structuralism. Each framework provides different theorisations of organisations and prompts different research questions. These frameworks may contribute to a geographical understanding of organisations. This is

of relevance to diabetes given the large number of organisations involved with the provision of diabetes care and education in New Zealand.

Diabetes education is vital for good diabetes management and self-care. To achieve and implement effective diabetes educational strategies it is vital to increase our understandings of diabetes education from the inside; from the point of view of those who receive education, and why people do not utilise the services that are available. The qualitative fieldwork within this study raised several important aspects. However, given the importance of diabetes education, more in-depth qualitative fieldwork needs to be undertaken. Fieldwork needs to be conducted in different parts of New Zealand and among different population groups, for example Maori communities and younger people, to gain a greater understanding of the barriers to utilising and accessing diabetes education.

It is also necessary to reach those are considered to be 'high risk' and 'hard to reach'. This is especially important given the associated risk factors, the insidious nature of type 2 diabetes, and the severity of complications that can result, if left untreated. How this can be achieved poses a challenge, however, it must be addressed to help reduce the personal and financial burden diabetes in the future.

9.6 Concluding Statement

Diabetes is a serious health problem that currently affects 115,000 New Zealanders. This figure is expected to increase markedly in the future. It is also estimated that a further 60,000 people are unaware that they have diabetes. Diabetes education is vital for increasing awareness of diabetes in the community and helping people with diabetes to achieve better diabetes management and avoiding complications. The diabetes societies have a key role in providing education and creating awareness in the community through social interaction and social support. The role of the diabetes societies in New Zealand must be increasingly recognised by health policy decision makers and incorporated into strategic frameworks. The utilisation of such educational services is a complex issue. Many factors can influence and act as barriers to the utilisation of such services and must not only be recognised but understood, from the patients' perspective, when health care planning is undertaken at

the national, regional and local levels. To improve diabetes educational services there needs to be an understanding of the importance of consumers, and their perceptions and experiences with diabetes education.

The predicted increase of diabetes rates in the future poses many challenges at all levels of society. What we need is health care not sick care, interventions that take place before drastic solutions are needed. Education and early intervention can help to reduce the social and economic burden of diabetes. Certainly, any approach to dealing with diabetes must begin with education. People need to be aware of diabetes, its severity and the preventative strategies that can be taken to avoid diagnosis and complications. Education needs to be undertaken at all levels of society, especially people and places considered 'hard to reach' and 'high risk' to increase awareness of diabetes generally and the associated risk factors (Barrett 2004). These challenges must be addressed now if the human time bomb is to be prevented.

Personal Communication

The following is a list of interviewees from official and public organisations. It does not contain those interviews conducted as a part of the qualitative fieldwork or with the presidents of the diabetes society. Interviews are listed in chronological order.

Professor Don Beaven, 2004, November 26. Patron of Diabetes New Zealand.

Professor Don Beaven. 2003, December 05. Patron of Diabetes New Zealand.

Maggie Wilson. 2004, March 10. Diabetes Educator, Pegasus Health, Christchurch.

Dr. Pauline Barnett. 2004, July 08. Senior Lecture, Department of Public Health and General Practice, Christchurch School of Medicine and health Sciences, Christchurch, New Zealand.

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APPENDICES

APPENDIX 1

Questionnaire to Diabetes Society Members

coding number C ☐

ABOUT YOU AND YOUR DIABETES

1. What type of diabetes do you have? ☐ Type 1
☐ Type 2
☐ Don't know
☐ Other, please specify _____
2. What treatment do you have for your diabetes?
☐ Diet and/or exercise
☐ Insulin injections
☐ Tablet treated
☐ Both insulin and tablets
☐ Other, please specify _____
3. What age did your diabetes start? _____
- 4a. Does anyone in your immediate family, 1st generation, (mother, father, brother, sister or child, not spouse or partner) have diabetes? ☐ yes ☐ no
- 4b. Does anyone in your 2nd generation family (aunties, uncles etc) have diabetes?
☐ yes ☐ no
5. Do you think about things like, the food you eat and physical activity and the affect they have on your health? ☐ yes ☐ no
- If yes how often?
☐ everyday ☐ once a week ☐ once a month ☐ once a year
6. Please list up to 4 of the most important risk factors leading to diabetes:
1. _____
2. _____
3. _____
4. _____
7. Please list up to 3 medical complications that can result from diabetes:
1. _____
2. _____

3. _____

8. Who do you think is at most risk of getting diabetes, both type 1 and type 2?

Type 1: _____

Type 2: _____

DIABETES CARE

9. Do you meet regularly with other people who have diabetes? ☐ yes ☐ no

If so, do you share information relating to diabetes and diabetes care? ☐ yes ☐ no

10. If a family member has diabetes, do they talk to you about their diabetes and how you can stop/prevent diabetes? ☐ yes ☐ no

11. Do you feel satisfied with your level of support, from your family, friends, whanau, kainga, aiga, faoa? (Please tick a level that best fits how you feel)

☐ Very satisfied

☐ Quite satisfied

☐ Neither satisfied or dissatisfied

☐ Quite dissatisfied

☐ Very dissatisfied

12a. Who do you see first for your diabetes care?

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Specialist, if so where are they located, eg hospital _____

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Your local Diabetes Society, eg Diabetes Christchurch

☐ Your family, whanau, kainga, aiga, faoa

☐ Other, please specify _____

12b. Who do you see or contact first for your after hours diabetes advice?

☐ A health phone line, if so what is the name of this service _____

☐ Ambulance services

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Specialist, if so where are they located, eg hospital _____

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Your local Diabetes Society, eg Diabetes Christchurch

☐ Your family, whanau, kainga, aiga, faoa

☐ Other, please specify _____

12c. Are you satisfied with the level of emergency/after hours diabetes care?

1. ☐ Very satisfied

2. ☐ Somewhat satisfied

3. ☐ Neither satisfied or dissatisfied

4. ☐ Dissatisfied

5. ☐ Very dissatisfied

If you ticked option 4 or 5 please explain why? _____

13. How often do you go to your Doctor/GP for diabetes care?

☐ every week ☐ every month ☐ every 3 months ☐ every 6 months ☐ every year

14. Please tick the "yes" box if the following are important for your diabetes care:

a. Nutritional advice: yes ☐ If yes, where do you go for this advice?

Christchurch

☐ Your local Diabetes Society, eg Diabetes

☐ Your local diabetes specialist, if so where are they located, eg hospital, diabetes centre _____

☐ Diabetes Life Education

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Dietician

☐ Group education classes, if so who ran these _____

☐ Diabetes support groups, if so who ran these _____

☐ Your relatives/whanau/kainga/aiga/faoa

☐ Other, please specify _____

b. Diabetes management

advice: yes ☐

If yes, where do you go for this advice?

☐ Your local Diabetes Society, eg Diabetes

Christchurch

☐ Your local diabetes specialist, if so where are they are they located, eg hospital, diabetes centre?

☐ Diabetes Life Education

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Dietician

☐ Group education classes, if so who ran these _____

☐ Diabetes support groups, if so who ran these _____

☐ Your relatives/whanau/kainga/aiga/faoa

☐ Other, please specify _____

c. Exercise advice/: yes ☐ If yes, where do you go for this advice?
classes

Christchurch

☐ Your local Diabetes Society, eg Diabetes

☐ Your local diabetes specialist, if so where are they located, eg hospital, diabetes centre _____

☐ Diabetes Life Education

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Dietician

- ☐ Group education classes, if so who ran these _____
- ☐ Diabetes support groups, if so who ran these _____
- ☐ Your relatives/whanau/kainga/aiga/faoa _____
- ☐ Other, please specify _____

- d. Diabetes support? yes ☐ If yes, where do you go for this advice?
- ☐ Your local Diabetes Society, eg Diabetes Christchurch
 - ☐ Your local diabetes specialist, if so where are they located, eg hospital, diabetes centre _____
 - ☐ Diabetes Life Education
 - ☐ Your Doctor/GP
 - ☐ Your Doctor/GP's nurse
 - ☐ Your local Diabetes Nurse Educator
 - ☐ Nurse Maude Diabetes District Nurses
 - ☐ Dietician
 - ☐ Group education classes, if so who ran these _____
 - ☐ Diabetes support groups, if so who ran these _____
 - ☐ Your relatives/whanau/kainga/aiga/faoa _____
 - ☐ Other, please specify _____

15. Please tick the "yes" box if you need help with the following:

- a. Collecting tablets yes ☐ If yes, who usually helps you?
- ☐ Your local Diabetes Society, eg Diabetes Christchurch
 - ☐ Your local diabetes specialist, if so where are they located, eg hospital, diabetes centre _____
 - ☐ Diabetes Life Education
 - ☐ Your Doctor/GP
 - ☐ Your Doctor/GP's nurse
 - ☐ Your local Diabetes Nurse Educator
 - ☐ Nurse Maude Diabetes District Nurses
 - ☐ Your local Pharmacist
 - ☐ Dietitian
 - ☐ Your relatives/whanau/kainga/aiga/faoa _____
 - ☐ Diabetes support groups, if so who ran these _____
 - ☐ Other, please specify _____

- b. Collecting insulin yes ☐ If yes, who usually helps you?
- ☐ Your local Diabetes Society, eg Diabetes Christchurch
 - ☐ Your local diabetes specialist, if so where are they located, eg hospital, diabetes centre _____
 - ☐ Diabetes Life Education
 - ☐ Your Doctor/GP
 - ☐ Your Doctor/GP's nurse
 - ☐ Your local Diabetes Nurse Educator
 - ☐ Nurse Maude Diabetes District Nurses
 - ☐ Your local Pharmacist

- ☐ Dietician
☐ Your relatives/whanau/kainga/aiga/faoa
☐ Diabetes support groups, if so who ran these _____
☐ Other, please specify _____

c. Visits to the
Diabetes specialist?

yes ☐

If yes, who usually helps you?

☐ Your local Diabetes Society, eg Diabetes

Christchurch

☐ Your Doctor/GP

☐ Your Doctor/GP's nurse

☐ Your local Diabetes Nurse Educator

☐ Nurse Maude Diabetes District Nurses

☐ Dietician

☐ Your relatives/whanau/kainga/aiga/faoa

☐ Diabetes support groups, if so who ran these _____

☐ Other, please specify _____

DIABETES EDUCATION

16. Please indicate with a tick how you feel about the all of the following types of education:

<i>Type of education</i>	<i>Strongly prefer</i>	<i>Usually prefer</i>	<i>No views</i>	<i>Don't usually prefer</i>	<i>Never prefer</i>
Advice from your Doctor/GP					
Advice from your Doctor/GP's nurse					
Advice from Nurse Maude Diabetes District Nurses					
One on one education with your diabetes Nurse Educator					
Otautahi Maori Regional Diabetes Society					
Pacific Diabetes Clinics at Diabetes Centre					
Group education classes**					
Diabetes Society meetings					
Diabetes support groups					
Your family/whanau/kainga/aiga/faoa					
Internet websites					
Email chat rooms					
Books					
Video					
Other, please specify					

**If so who ran these education classes? _____

17. Please indicate with a tick how much of your diabetes education has been provided by the all of the following:

<i>Education provider</i>	<i>Almost all</i>	<i>Quite a lot</i>	<i>Some</i>	<i>Hardly any</i>	<i>None at all</i>
Your local Diabetes Society, eg Diabetes Christchurch					
Your Doctor/GP					
Your Doctor/GP's nurse					
Your relatives/whanau/kainga/aiga/faoa					
Your local Diabetes Specialist					
Nurse Maude Diabetes District Nurses					
Otautahi Maori Regional Diabetes Society					
Pacific Diabetes Clinics at Diabetes Centre					
Internet websites you've found					
Books you have read					
Diabetes support groups					
Group education classes**					
Other, please specify					

**If so who ran these education classes? _____

If you have any other comments regarding types education or where you get your diabetes education from please feel free to write them below:

18.

Please indicate with a tick how often you get information from all of the sources below.

Tick “yes” or “no” regarding if the information is clear and if it is easily available to you:

<i>Source of information</i>	<i>Nearly always</i>	<i>Often</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Never</i>	<i>Is the info clear</i>	<i>Is the info easily available</i>
Internet websites that you have found						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Email chat rooms						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Pamphlets/brochures/books that you have read						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Word of mouth, talking to family, whanau, friends, kainga, aiga, faoa						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your local Diabetes Society, eg Diabetes Christchurch						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your local Diabetes support group						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your local Diabetes Specialist						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your Doctor/GP						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your Doctor/GP's nurse						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your local Diabetes Nurse Educator						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no
Talking to your Nurse Maude Diabetes District Nurse						<input type="checkbox"/> yes <input type="checkbox"/> no	<input type="checkbox"/> yes <input type="checkbox"/> no

Please feel free to write any other comments below:

19. Has diabetes education helped you to make changes in your life that mean you can better manage your diabetes? ☐ yes ☐ no
If not why not? _____

20. Are you interested in new diabetes technology and research? ☐ yes ☐ no

YOU AND THE DIABETES SOCIETY

21. Do you use the services of your local diabetes society? ☐ yes ☐ no

If so how often?

☐ every week ☐ every month ☐ every 3 months ☐ every 6 months ☐ every year

22. How did you first find out about your local diabetes society (please tick one)?

☐ Your Doctor

☐ Your Practice Nurse

☐ Friends, family, whanau, kainga, aiga, faoa who already use the diabetes society

☐ Internet

☐ Pamphlets

☐ Other, please specify _____

23. What is your level of involvement with your diabetes society, for example, attending meetings, helping with activities like diabetes awareness week?

☐ Always involved

☐ Often involved

☐ Sometimes involved

☐ Occasionally involved

☐ Never involved

24. How does the diabetes society help you? _____

25. Has being a member of your diabetes society allowed you to help others with diabetes? ☐ yes ☐ no

If yes, how have you helped others? _____

26. What do you think the main purpose of your diabetes society is? _____

27. What would you say the main ways diabetes societies have helped people with diabetes in your area? _____

28. Which of the following groups would you say are most likely to be members of diabetes societies?

- ☐ No particular group – all people with diabetes
- ☐ People with higher levels of education
- ☐ Maori and Pacific Island peoples
- ☐ Older people
- ☐ Other, please specify _____

29. What do you think is the best way to deal with the huge growth of diabetes?

- ☐ Through the diabetes society
- ☐ Through the medical centres, Doctors, Practice Nurses and primary health organisations
- ☐ Through new diabetes technology
- ☐ By encouraging self-care and self-monitoring
- ☐ Through advertising
- ☐ Other, please specify _____

30. How effective do you think your local diabetes society has been in dealing with the increase in diabetes in your area?

1. ☐ Very effective 2. ☐ Somewhat effective 3. ☐ Neither effective or ineffective
4. ☐ Ineffective 5. ☐ Very ineffective

If you ticked option 4 or 5 please explain why? _____

Thank you for answering this questionnaire your participation is greatly appreciated, now we just need some personal details.

31. What age are you?

- ☐ 18 – 30
- ☐ 30 – 40
- ☐ 40 – 50
- ☐ 50 – 60
- ☐ 60 – 70
- ☐ 70+

32. Are you? ☐ Male
 ☐ Female

33. Which ethnic group do you belong to?

- ☐ New Zealand European
- ☐ Maori, tribal affiliation please specify _____
- ☐ Samoan
- ☐ Cook Island Maori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Other please state _____

34. What is your main daily activity?

- ☐ Paid work: type of work _____
Does your work involve?

- ☐ High level of activity
- ☐ Medium level of activity
- ☐ Not much activity
- ☐ Looking after your home
- ☐ Retired
- ☐ Other, please explain _____

OPTIONAL

If you would be interested in participating in a follow up interview at a later date it would be appreciated if you could provide your name and contact phone number below, however, this is optional.

Name: _____

Address: _____

Phone number: _____

**IF YOU HAVE ANY QUESTIONS OR ARE INTERESTED IN THE RESULTS
OF MY RESEARCH THEN PLEASE FEEL FREE TO CONTACT ME ANY**

TIME:

Pam Howes, 03 3667001 extn 8141, pah61@student.canterbury.ac.nz

***THANK YOU FOR TAKING THE TIME TO FILL IN THIS
QUESTIONNAIRE***

APPENDIX 1a

Letter of Introduction for Questionnaire Respondents

Geographies of Diabetes: Interfacing consumers and health professional's perceptions of care in New Zealand

This project is being carried out for the fulfilment of a Master of Arts by Pam Howes under the supervision of Associate Professor Ross Barnett and Dr Jamie Pearce, Geography Department, University of Canterbury, and with assistance from Professor Don Beaven and Diabetes New Zealand Inc.

Diabetes is a serious health concern for New Zealand and New Zealanders. Recent health surveys have forecasted that diabetes could reach epidemic proportions in the near future. Health services and education have a crucial role in maintaining a healthy population. The aim of this project is to examine the quality and effectiveness of diabetes education and care in New Zealand. This will be achieved by analysing the organisation of diabetes education and care at the national level, and by conducting an in-depth analysis of educational provision in Christchurch by exploring the barriers to using these services.

This questionnaire is anonymous; and you will not be identified as a participant without your consent. You may withdraw your participation at any time. By completing the questionnaire it will be understood that you have agreed to take part in the project and that you agree to the publication of the results of this project, with the understanding that all results will remain anonymous.

If you choose to participate in a follow up interview at a later date, you can indicate your interest at the end of this questionnaire and you will be contacted accordingly, your participation in the follow up interview is optional.

Please return this questionnaire to me in the self addressed stamped envelope that is provided.

If you have any questions or concerns about the project itself or your participation in it, or would like to see the results once completed please feel free to contact me any time at (03) 3667001 ext: 8141 or pah61@student.canterbury.ac.nz Ross Barnett can be contacted at (03) 3667001 ext: 7915 and Jamie Pearce can be contacted at (03) 3667001 ext: 7943.

THANK YOU FOR YOUR TIME

APPENDIX 2

Output from SPSS: Questionnaire Data Analysis

05 Aug 04 SPSS for MS WINDOWS Release 6.1

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RURALURB by INVOLVEA

Count						
Exp value						
		INVOLVEA				
		1.00	2.00	3.00	4.00	ROW TOTAL
RURALURB	1.00	11 6.3	9 3.4	13 10.4	12 24.9	45 14.9%
	2.00	31 35.7	14 19.6	57 59.6	155 142.1	257 85.1%
COLUMN TOTAL		42 13.9%	23 7.6%	70 23.2%	167 55.3%	302 100.0%

Chi-Square	Value	DF	Significance
Pearson	23.45323	3	0.00003
Likelihood Ratio	21.67756	3	0.00008
Linear by linear Association	17.73034	1	0.00003

Maximum Expected Frequency: 3.427

Cells with Expected Frequency < 5: 1 of 8 (12.5%)

Number of Missing Observations: 35

APPENDIX 3

Letter of Introduction for Focus Group Participants

“Geographies of diabetes: interfacing consumers and health professionals perceptions of care and education”

Hi,

My name is Pam Howes and I'm currently a Masters student in the Geography department at the University of Canterbury researching diabetes education in New Zealand. This project has been reviewed and accepted by the University's human ethics committee.

The aim of this project is to examine the quality and effectiveness of diabetes education and care in New Zealand. This will be achieved by analysing the organisation of diabetes education and care at the national level, and by conducting an in-depth analysis of educational provision in Christchurch and exploring the barriers to using these services.

This focus group will last for about 30 minutes, but please feel free to withdraw your participation at any time.

I am interested in talking with you about your diabetes, your diabetes education, where you receive it and how you feel about it.

Please note that this discussion will be transcribed and material from which may be used in the write up of my findings. However, you can be assured of complete confidentiality as all comments will remain anonymous. If you wish to view a copy of the transcript please feel free to ask.

Your participation and time is greatly appreciated. If you have any questions, concerns or thoughts later on please feel free to contact me any time at university: 3667001 extension 8141. Alternatively you may like to contact my supervisors, Ross Barnett 3667001 extension 7915 or Jamie Pearce 3667001 extension 7943.

Thank very much for your time.

APPENDIX 3a

Focus Group Schedule

You and your diabetes

Who first told you that you had diabetes? How did this make you feel

Did you have the chance to ask questions?

Were you referred on to anyone else for further info?

Before this did you know what diabetes was?

Did you think that you might have been at risk?

What does having diabetes mean to you? How does it affect your life?

Diabetes services

Who tells you most about your diabetes?

What do you feel you get out of coming to this group?

What do you like/dislike about this care and education?

what type of education do you prefer ie one on one or group?

What other people/groups do you think are involved with diabetes care and education in Christchurch?

Have you heard of diabetes Christchurch?

Do you know what they do?

Have you ever been to any of these places?

What stops you from going to these places?

Do you know of other people who have diabetes who don't come to this group, why do you think they might not come?

Do you feel that the system and organisation of diabetes care in Christchurch is adequate?

Do you get support from your family and friends?

How do you feel about other people knowing you have diabetes?

Do you find it easy to talk about your diabetes to other people? Talk to your family about diabetes?

When you go to the doctor and they tell you to do certain things in relation to your diabetes or your health generally do you feel comfortable with these things, do you find them easy to achieve? –

Are they a priority?

If not what stops you?

How do you feel about putting into place in your lives the health messages that you read about and hear about?

What stops you from doing these things?

APPENDIX 4

Letter on My Behalf from the Medical Centre in Christchurch

Dear Sir/Madam,

I am writing this letter on behalf of Pam Howes who is currently researching Diabetes Education in New Zealand.

This project is being carried out for the fulfilment of a Master of Arts, by Pam Howes, under the supervision of Associate Professor Ross Barnett and Dr Jamie Pearce at the Geography Department, University of Canterbury, and with assistance from Professor Don Beaven and Diabetes New Zealand Inc. The project has also been reviewed and accepted by the University of Canterbury Human Ethics Committee.

As you will be aware diabetes is a serious health concern for New Zealand and New Zealanders. Recent health surveys have forecasted that diabetes could reach epidemic proportions in the near future. Health services and education have a crucial role in maintaining a healthy population.

The aim of this project is to examine the quality and effectiveness of diabetes education and care in New Zealand.

We would be very grateful if you would be willing to participate in an interview, of about 30 minutes, at a time that is suitable to you.

We are interested in your perceptions of diabetes and the associated risk factors. How/ where/ if you receive your diabetes education, and how you feel about different providers, and if you experience any barriers to accessing diabetes care and education and/or health care and education more generally.

If you would be willing to participate in an interview please contact me (Pam) any time at university: 3667001 extension 8141, or please leave a message if I'm not there and I'll get back to you. Alternatively, please feel free to contact me at home: 3434207, or by email: pah61@student.canterbury.ac.nz to arrange a suitable time for you.

Thank you very much for your time. If you have any questions or concerns don't hesitate to contact myself, or my supervisors: Ross Barnett: 3667001 extension 7915 or Jamie Pearce 3667001 extension 7943.

Thank you, Regards
Practice Nurse Name (Medical Centre Name).
Pam Howes (University of Canterbury).

APPENDIX 5

Interview Schedule

You and your diabetes

Who first told you that you had diabetes? How did this make you feel

Did you have the chance to ask questions?

Were you referred on to anyone else for further info?

Were you told about the diabetes society? If so what did you think, how did you feel did you consider joining?

Before this did you know what diabetes was?

Did you think that you might have been at risk?

What does having diabetes mean to you? How does it affect your life?

Diabetes services

Who tells you most about your diabetes?

Do you feel comfortable with this person?

What do you feel you get out of coming to this group?

What do you like/dislike about this care and education?

what type of education do you prefer ie one on one or group?

What other people/groups do you think are involved with diabetes care and education in Christchurch?

Have you heard of diabetes Christchurch, diabetes life education and the diabetes centre?

Do you know what they do?

Have you ever been to any of these places?

What stops you from going to these places?

Do you know of other people who have diabetes who don't come to this group, why do you think they might not come?

Do you feel that the system and organisation of diabetes care in Christchurch is adequate?

Do you get support from your family and friends?

How do you feel about other people knowing you have diabetes?

Do you find it easy to talk about your diabetes to other people? Talk to your family about diabetes?

When you go to the doctor and they tell you to do certain things in relation to your diabetes or your health generally do you feel comfortable with these things, do you find them easy to achieve? - priority

If not what stops you?

How do you feel about putting into place in your lives the health messages that you read about and hear about? – is it important
What stops you

Does you have any questions for me or anything else to add?